IMPROVING THE UPTAKE OF VOLUNTARY HIV TESTING IN UK AFRICAN COMMUNITIES

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A dissertation submitted to the University of Bristol in accordance with the requirements of the degree of PhD in the Faculty of Medicine

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September 2006

Abstract

Background

The UK African population is disproportionately affected by HIV infection, and presentation is often late in the disease when treatment may be less effective. Much remains unknown about the cultural practices, beliefs and attitudes of Africans, with or at risk of HIV, against a background of economic deprivation, uncertain immigration status and 'dispersal' to settings outside London. This study explores the barriers to HIV testing in UK African communities in a setting outside the capital, from the perspectives of professionals and African people, and considers how the uptake of testing might be improved.

Methods

A qualitative study of professional and African views of HIV testing was undertaken. Interviews with key informants from a range of professional backgrounds explored their views, experiences and attitudes relating to HIV testing in Africans. In-depth interviews with African participants, of known and unknown HIV status, explored cultural norms and beliefs, perceptions of risk, knowledge and experience of HIV, access to services and issues relating to immigration and racism. Data were analysed using the constant comparative method derived from grounded theory approaches.

Findings

Complex influences and beliefs act as barriers to HIV testing amongst Africans in the UK. Key themes emerging from the data included competing priorities, fear, stigma and perceptions of risk. Cultural norms, spiritual beliefs, negative experiences of HIV in Africa and limited knowledge of treatment all strongly influenced attitudes to HIV testing. Whilst some professionals feared the charge of racism, targeted voluntary HIV testing was broadly acceptable to African people.

Implications

The findings of this research provide new insights into the barriers to HIV testing in UK African communities and point to a number of potentially important ways in which some may be ameliorated. They have application to primary care practice and wider implications for health promotion strategies, policy makers and clinicians.

Dedication and acknowledgements

My warmest thanks go to Professor Chris Salisbury, Dr Ali Heawood and Dr Nicola Low for their guidance and encouragement, so generously given throughout. Their combined expertise, which spans so widely, their endless enthusiasm and commitment, and their unfailing belief in me and in this project have all spurred me on. I count myself remarkably fortunate.

I am grateful to Professor Debbie Sharp who has supported this study from its inception, and who has encouraged me at every step. Without the opportunities and support she has given, this research would not have been possible.

The research was funded through a Researcher Development Award from the Department of Health and NHS R&D, and a grant awarded by the Scientific Foundation Board of the Royal College of General Practitioners. I offer my gratitude for both.

Most of all, my thanks go to all the participants in the study, without whom there would not have been a project. In particular, I am hugely indebted to the many African participants who were willing to share their often painful life stories with me. Without their openness this research would have been greatly impoverished.

This thesis is dedicated to my late father who was always my strongest advocate and my greatest ally.

Author's Declaration

I declare that the work in this dissertation was carried out in accordance with the Regulations of the University of Bristol. The work is original except where indicated by special reference in the text, and no part of the dissertation has been submitted for any other degree.

Any views expressed in the dissertation are those of the author and in no way represent those of the University of Bristol.

This dissertation has not been presented to any other University for examination either in the United Kingdom or overseas.

Signed Caroline Yandell

Date 30.04.07

Table of Contents

List of Figures and Tables

CHAPTER 1. INTRODUCTION

1.1. Setting the Scene

It is 25 years since the first case of Acquired Immune Deficiency Syndrome (AIDS) was identified. Since that time there has been a number of important developments in understanding and management of the disease. The Human Immunodeficiency Virus (HIV), the virus responsible for the development of AIDS, has been identified[1;2] and its biology elucidated.[3;4] Diagnostic tests have been established and improved,[5] and drugs and care systems that have been shown to be effective in modifying the disease process and reducing mortality have been developed.[6-8]

1.1.1. The scene in the United Kingdom

Despite the advances of the last quarter century the number of newly diagnosed cases of HIV infection in the UK continues to increase, most markedly since the year 2000. In the year 2004 more than 7000 new diagnoses were made, almost double the number four years earlier.[9] Further, it is estimated that about a third of the 58,300 people believed to be living with HIV are unaware of their infection, and preventable deaths in people with AIDS continue to occur.[9] Over recent years the number of diagnosed HIV infections acquired through sex between men and women has progressively increased; each year since 1999 newly diagnosed HIV infections acquired heterosexually have exceeded those from sex between men.[9]

HIV in UK African communities.

Most of the dramatic increase in heterosexually acquired infection has been in people who are from sub-Saharan Africa; the UK heterosexual HIV epidemic is intimately linked with that in sub-Saharan Africa and reflects historical and recent migratory patterns.[10] Most infections among African people are thought to be acquired before migration to the UK.[11] However, as the prevalent pool of HIV-

infected Africans continues to increase, so too will the potential for onward sexual transmission within Britain, especially among people of the same ethnic and cultural background.[12]

Not only do UK African communities carry a disproportionate burden of infection with HIV but they also present to treatment services later than other social groups.[10;13] The estimated prevalence of undiagnosed HIV infection in African born people living in London is almost 4%, whilst outside of the capital it is over 7%, which may reflect the dispersal of more recent migrant populations to areas outside London.[9] African people are therefore more likely to present to treatment services with advanced disease, not infrequently with an AIDS defining illness.[13]

Delayed access to HIV care by African people has important consequences for the individuals concerned and for wider public health. For the individual there may be avoidable morbidity and mortality whilst for public health there is potential for onward transmission of infection, late identification and management of infected contacts and increasing treatment costs associated with hospitalization and more expensive therapies.[14]

HIV testing

The promotion of HIV testing is an important component of primary and secondary HIV prevention strategies.[15] The threefold aim of improving the uptake of HIV testing is firstly to reduce the proportion of undiagnosed HIV infection within the community, second to ensure early access to treatment and care for those found to be infected, and third to limit further transmission.

When HIV testing first became available 20 years ago it was in the absence of treatment and in a context of discrimination. Infection with HIV was handled differently from other serious infectious diseases with emphasis being placed upon pre-test counselling and gaining specific consent, a trend which has been termed 'HIV exceptionalism'.[16] Although available within primary care settings, the great majority of HIV testing continues to be undertaken in specialist

genitourinary medicine settings.[17] With the advent of effective therapies there are calls for HIV testing to be more routinely available in primary care and approached more like other infectious diseases in which early diagnosis is essential for appropriate therapeutic and preventive measures.[18-21]

In recognition of the disproportionate burden of HIV within UK African Communities, the Department of Health's National Strategy for Sexual Health and HIV identified this group as a priority for targeted HIV prevention work.[15] In effecting its aim to reduce undiagnosed HIV infection the Strategy required that HIV testing be offered to all genitourinary medicine clinic attendees, whilst recognising that some people are reluctant to access this service and underlining the significant contribution to be made by general practitioners. The Framework for Better Prevention and Care developed by the African HIV Policy Network in partnership with the Department of Health and the National AIDS Trust similarly attaches considerable importance to the reduction of undiagnosed HIV infection in Africans, setting it as a core prevention aim.[22]

1.2. Aim of the research and research design

General aim

Given the importance of reducing undiagnosed HIV infection in African people and that the case for diagnosing patients at an early stage of HIV infection has been made, it is clear that there is a need to improve the uptake of HIV testing in UK African communities. What is not clear is how this might best be achieved.

The broad aim of this research is therefore to address the general question "How can we improve the uptake of voluntary HIV testing by UK African communities?"

The research setting

The majority of Africans with HIV infection in the UK live in London, although in recent years the proportion outside the capital has been rising as African

people have increasingly settled in, or been 'dispersed' to other parts of the country by the UK National Asylum Support Service.[9] The most marked increase in the rate of new HIV diagnoses has been seen in areas outside London and the level of undiagnosed infection is nearly twice as high.[9;23] It is also likely that in areas where the increase in migrants from sub-Saharan Africa has been more recent, HIV services and African community support organisations may be less well established.[22;24]

For these reasons, this study explored the research question in a setting outside of London. The choice of the city of Bristol was both pragmatic (it is the researcher's base) and informed by reports of increasing numbers of African patients presenting to HIV services in the city, often with advanced HIV disease.

The city of Bristol (population 380,000) has a heterogeneous African population of several thousand people, although the exact size is difficult to quantify.[25;26] HIV services in Bristol have seen a rise in the number of new cases of HIV in each year since 2001 rising from 40 new diagnoses in the year 2001 to over 100 new cases in 2004. African patients account for over 40% of new cases.[27] Many of these patients present at a late stage of disease resulting in an increase in the number of hospital admissions over the same period and a small number of deaths each year.[27]

The research design

The process of HIV testing involves both professionals and African patients. From the outset the researcher was concerned to explore the barriers to HIV testing, and how they might be overcome, from the perspectives of both professionals and African people.

Of key concern was the intention to recognise the social (and professional) contexts of people's understandings and experiences and to uncover people's own meanings and worldviews. Further, the nature of the subject being researched would necessarily involve uncovering potentially sensitive and

intensely personal information, made more difficult by the stigma attached to HIV.

Taking all these factors into account it was therefore crucial to adopt a flexible research design and a qualitative approach, to allow exploration of the 'social causation that lies beneath observable patterns'.[28]

Thus, to address the aim of the research the following design was established:

- Firstly, a critical narrative review of the literature in the fields of HIV testing and HIV in African communities. The review was to focus on two particular aspects of this broad subject, and to identify gaps in the literature. With regard to the literature on HIV testing it was to focus particularly on testing in the UK and to consider the extent to which primary care was an appropriate setting for testing to be undertaken. With regard to HIV in African communities, the review was to focus particularly on the needs, experiences and beliefs of UK African communities and to consider the extent to which these influence decisions about HIV testing.
- Secondly, a process of sensitisation in which the researcher would use observational methods (both unstructured non-participant observation and participant observation) in a variety of HIV-related and African community settings.
- Thirdly, the key issues to be mapped out through key informant interviews with a range of professionals working in the field of HIV in Bristol. Initially designed as 'fact finding' devices, these interviews also enabled exploration of professionals' views and experiences of HIV testing and care of their African patients.
- Fourthly, individual in-depth interviews with African participants in Bristol. To reflect the evolving and iterative nature of qualitative research design, the issues covered in these interviews were to be shaped by the literature and the data from interviews with professionals.

Originality of the research

This study has a number of features that mark its originality. Few studies of HIV in African communities have been conducted outside of London and this is the first to take place in Bristol. It is particularly focused on issues around HIV testing and explores the perspectives of professionals and African people, yielding the opportunity to compare and contrast these views. Further, the African participants include both those who have and have not been tested for HIV and amongst those who have been tested, both those whose HIV status is positive and negative. Thus, it is possible to explore factors other than ill health that are involved in the decision to undertake testing. Finally, the researcher is a general practitioner (GP) and brings to the research her primary care perspective and her interest in the potential role of primary care in HIV.

1.3. Outline of the thesis

The next chapter will review the literature around HIV testing and HIV in UK African communities. It will identify a range of issues to be considered, highlight the gaps in the current literature and help to clarify the research questions to be addressed in this study.

Chapter 3 will discuss the methodology adopted and outline the empirical methods used for the fieldwork and analysis.

Chapters 4 and 5 will present a descriptive and interpretive account of the data from interviews with professionals and African participants.

In Chapter 6 the two sets of findings will be drawn together and a broader conceptual discussion of the issues emerging from the study as a whole will be developed and interpreted in the light of the literature. The chapter will also discuss the methodology and methods adopted, noting issues of reflexivity. Finally, Chapter 6 will consider the implications of the study's findings.

Chapter 7 will provide brief concluding thoughts to draw the thesis to a close.

CHAPTER 2. LITERATURE REVIEW

2.1. Introduction

The aim of this chapter is to provide a comprehensive narrative review of the academic literature that provides the background to this research into improving the uptake of HIV testing by UK African communities.

The process of collecting and reviewing the literature continued throughout the study period and the review itself was subjected to revisions as the investigation progressed. Much additional material was reviewed that cannot be included due to space constraints. That which is most relevant to the study has been incorporated in this chapter.

The next section will briefly outline the methods used to identify and access the literature, and provide reflections upon the scope of the review, before a structured account of the relevant literature is presented.

2.1.1. The process and scope of the literature review

The purpose of the search strategy for the review was to identify material that would highlight and inform a range of issues to be considered, uncover gaps in the current literature and help to clarify the research questions to be addressed in this study. A range of sources was sought and a number of techniques employed to gather the material. Initially this involved searches on a range of electronic bibliographic databases including EMBASE, MEDLINE, PsycINFO and CINAHL, using key word searches. There is a vast amount of literature relating to HIV and AIDS and early broad searches resulted in huge lists of references many of which were not directly relevant to the current study. To increase the specificity of the search to focus particularly on migrant Africans and UK based research, the search strategy used combinations of key words including: 'HIV', 'migrant', 'migration', 'test', 'testing', 'Black African', 'UK', 'Africa', and 'sub-Saharan'. In general, research conducted in sub-Saharan Africa, research focusing

on men who have sex with men and much laboratory or clinically based research provided useful background reading but for brevity and focus is excluded from this review unless cited in included references.

Further material was identified through the bibliographies of retrieved articles and by hand searching journals. 'Grey literature' and expert working group, policy and surveillance reports were identified through references in retrieved articles and by searching the websites of a range of HIV related voluntary and statutory bodies.

The review was not restricted to particular study designs and includes both qualitative and quantitative studies. However the majority of studies of African communities in the UK are observational. Whilst the review refers to a small number of randomised controlled trials of treatments for example, these are generally cited as background material and it is not the purpose of this review to consider them in detail. A large proportion of the material relating to HIV in UK African communities is available as 'grey publications': reports from governmental and non-governmental organisations, online material and conference abstracts. It was therefore important that the review be relatively inclusive.

As set out in Chapter 1, this study aims to address the broad question of how to improve the uptake of HIV testing by UK African communities. Whilst beginning with introductory and background material, the remainder of this chapter is largely organized around the two key aspects of this question, namely HIV testing and HIV in UK African communities. The final included literature is grouped under the following topic headings:

General background: a brief review of the aetiology and clinical aspects of HIV and AIDS.

Epidemiology and growth of the epidemic: an overview of the global, African and UK epidemics based largely on governmental and non-governmental agency 'grey publications'.

HIV testing: material related to the testing process and issues arising from it, including confidentiality and 'exceptionalism' with a particular focus on primary care.

HIV in UK African communities: this major section reviews the extent of the HIV epidemic in UK Africans, before considering the literature relating to culture, beliefs and experiences of being a migrant as they relate to HIV. Research giving insight into the needs and experiences of African people living with HIV is reviewed along with the available literature on access to and use of HIV related services.

Finally, the chapter concludes with a summary of the gaps identified by the literature review and the specific research questions to be addressed by this study.

2.2. General background

The first cases of Acquired Immune Deficiency Syndrome (AIDS) were recognised amongst homosexual men in America in 1981 following reports of an aggressive form of Kaposi's sarcoma and of *Pneumocsytis carinii* pneumonia, the name and terminology of AIDS being adopted in August 1982.[29-32]

It soon emerged that the disease was not confined to the homosexual population, with the identification of cases in intravenous drug users, Haitian people and haemophiliacs.[33-35] It also became clear that AIDS was to be found beyond the USA; throughout 1982 there were separate reports of the disease occurring in a number of different countries.[36] Furthermore, the disease which had been known as 'slim' in Africa was subsequently recognised as AIDS.[37]

In May 1983 a potential viral cause of the disease, lymphadenopathy-associated virus (LAV), was isolated by investigators at the Institute Pasteur, France.[1] A year later Dr Robert Gallo of the National Cancer Institute in the United States of America, claimed to have isolated the virus responsible for AIDS, a newly discovered subgroup of the human T-cell leukaemia virus family, designating it

HTLV-III.[2] A number of further reports eventually clarified that LAV and HTLV-III were the same entity and in March 1985 the first blood test to identify the presence of the LAV/HTLV-III virus was licensed by the U.S. Food and Drug Agency.[38]

In May 1986 The International Committee on the Taxonomy of Viruses ruled that both names should be dropped and a new name adopted - the Human Immunodeficiency Virus (HIV).[39]

A definition of AIDS was first developed in the USA in 1982 and has changed over the years as it has been recognised that the disease has a wide range of clinical manifestations. Current definitions are based on the presence of specific indicator diseases (AIDS defining conditions), laboratory evidence of HIV infection and laboratory evidence of severe immunosuppression.[32;40-42] The details of diagnosis in the presence or absence of laboratory facilities, together with case definitions adopted for surveillance purposes can be found in Appendix 1.

2.2.1. Clinical aspects of disease

The term AIDS refers to the most severe clinical manifestations of infection with HIV and includes specific opportunistic infections, HIV-induced pathological conditions and associated cancers. Infection is believed to persist for life although few people progress to AIDS within the first 3 years of infection. Within 10 years, without treatment, approximately 50% of all HIV infected individuals will have developed AIDS.[43] This reflects the chronic nature of the disease which is hallmarked by a gradual deterioration of the host's immune system. This is characterised by the depletion of CD4 helper T lymphocytes, the loss of which can explain most of the pathological sequelae of HIV infection. Soon after a person becomes infected, the number of CD4 lymphocytes begins to drop from its normal value of about 1000 x 10^6 cells/l at a variable rate ranging from approximately 40 - 80 x 10^6 cells/l per year.

Acquisition of the virus is often followed by a brief flu-like illness corresponding to the period of antibody development. This seroconversion illness is generally followed by a phase of asymptomatic infection that persists for an average of ten years, during which time the viral load falls to low levels, the rate of HIV replication is slow and CD4 counts are generally above 350 x 10^6 cells/l.[44] Over a number of years there is a progressive deterioration of the immune system which is initially reflected in less severe clinical conditions, including diarrhoea, weight loss, oral candidiasis and generalised lymphadenopathy. As the immune system is progressively compromised, the presenting illnesses are increasingly severe; opportunistic infections and cancers, which the immune system would normally prevent, can occur in almost all of the body systems. Eventually a diagnosis of AIDS is made when one or more specific AIDS defining conditions have developed, which for most conditions usually occurs in patients with CD4 counts of less than 200 x 10^6 cells/l.[44;45]

2.2.2. The virus and its transmission

There are currently known to be two distinct viruses which cause AIDS, HIV types 1 and 2 (HIV-1/HIV-2). Epidemiological and genetic evidence suggests that they are zoonoses (human infections originating from animals), acquired via several independent transmission events from the chimpanzee (*Pan troglodytes*) and sooty mangabey (*Cercocebus atys*) respectively.[46;47]

Worldwide, the predominant virus is HIV-1, which is responsible for the vast majority of infections globally, HIV-2 being very rare outside of West Africa. The commonest mode of transmission of the virus is through sexual intercourse, with heterosexual transmission being dominant in most developing countries. Other routes of transmission are through the receipt of infected blood or blood products, donated organs and semen, through the sharing of contaminated needles, and from mother to child. Although there was a great deal of public concern when AIDS first came to light, the virus is not spread by casual or social contact.[48;49]

2.2.3. Treatment

Treatment for HIV infection can be broadly divided into two main types, namely specific antiviral agents that inhibit viral replication and treatment or prophylaxis of its complications (opportunistic infections and tumours).

The first drug to be licensed for treatment of HIV infection was azidomthymidine (AZT) following the early results of a randomised placebo controlled trial in 1987.[50] This and subsequent early drugs are Nucleoside Reverse Transcriptase Inhibitors (NRTI) and together with the second group of drugs in use, Non-Nucleoside Reverse Transcriptase Inhibitors (NNRTI), inhibit reverse transcriptase and therefore viral replication. Protease Inhibitors (PI), which inhibit viral protease resulting in the production of immature virus particles, are the third group in use.

Since 1996 these drug classes have been widely used in combination in the developed world. Highly active antiretroviral therapy (HAART) refers to a combination of at least three drugs that typically includes a PI or a NNRTI and two NRTIs. Since the introduction of HAART the prognosis for HIV positive patients has improved dramatically in populations with access to these treatments.[6;7;51-54] Inhibition of viral replication brings partial reconstitution of the immune system in most patients, substantially reducing the risk of clinical disease progression and death.[8] Where possible, the objective is to sustain plasma viral load to below 50 copies per ml and thereby minimise the risk of emergence of viral strains resistant to drugs.[55]

The optimal time to initiate treatment has not been established in clinical studies although it is known that CD4 count and plasma viral load are predictors of the estimated risk of progression to AIDS, which is a factor in the determining when to start treatment.[56;57] The motivation of the patient to start and adhere to therapy are also important considerations, which in turn are affected by the potential for significant drug toxicity.[8]

Clinical practice across Europe and North America varies, although most clinicians would consider initiating therapy in patients with a CD4 count of 200-500 x 10^6/l and in all patients who are symptomatic. The British HIV Association (BHIVA) treatment guidelines recommend that a CD4 count of 200 x 10^6/l is the minimum level for starting treatment.[58]

Many people in the developing world do not have access to treatment and have not benefited from the treatment advances in Europe and North America. The World Health Organisation (WHO) estimates that only 8% of those in developing countries who need antiretroviral therapy are currently receiving it and coverage in Africa is only 2%.[59] In 2003 the WHO announced its '3 by 5' initiative to make antiretroviral therapy available to 3 million people by 2005, although this target was not realised.[59] The expansion of the provision of drug therapy will require, in addition, the provision of suitable laboratory monitoring of treatment in order to minimise the risk of drug resistance and to optimise therapy.[60]

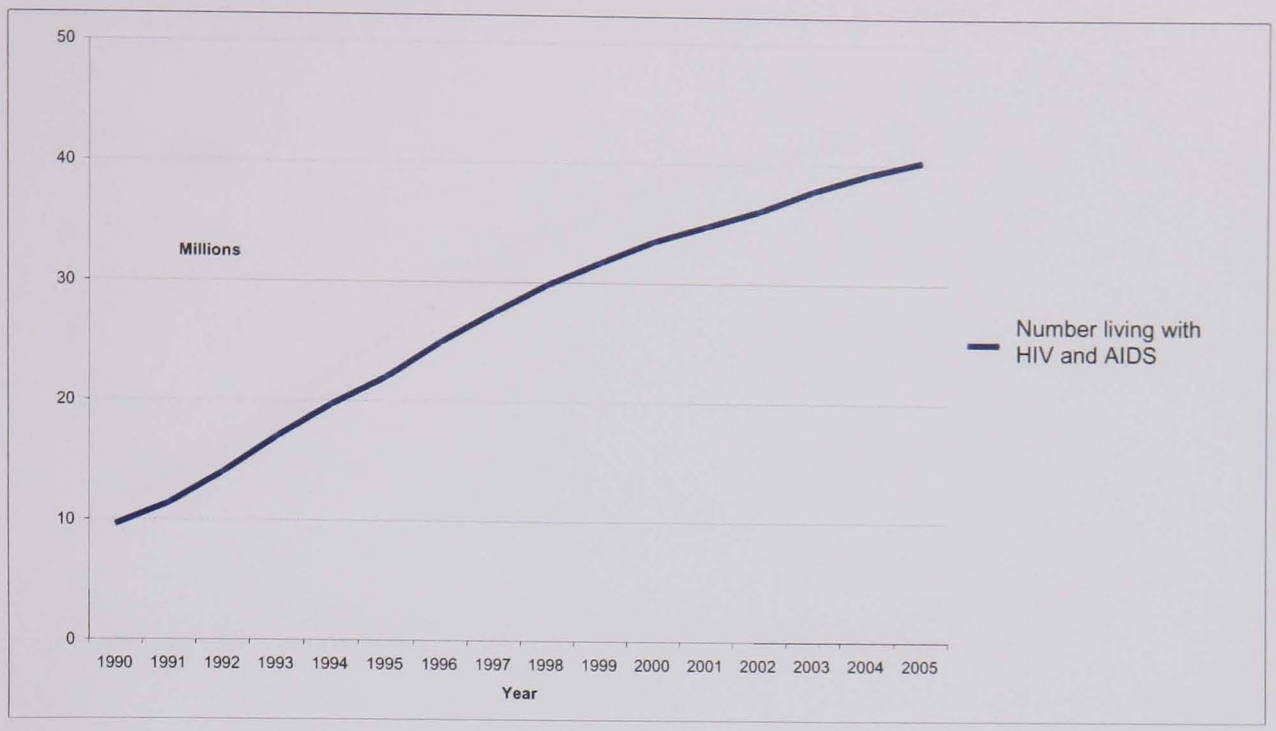
2.3. Epidemiology and growth of the epidemic

2.3.1. Global overview

Since the first AIDS case was diagnosed in 1981, the spread of the AIDS epidemic has been unparalleled. The expansion of AIDS is relentless and the number of people living with HIV continues to rise.

According to the Joint United Nations Programme on HIV/AIDS (UNAIDS), by the end of 2005 an estimated 40.3 million people were living with HIV, with 4.9 million people newly infected in 2005, the greatest number in any single year since the beginning of the epidemic. Since the first cases of AIDS were identified in 1981 over 25 million have died of the disease, 3.1 million in the year 2005 alone.[61] The growth of the epidemic is shown in Figure 1.

Figure 1: Global AIDS epidemic 1990 - 2005



Data source: UNAIDS reports[61;62]

2.3.2. Epidemiology of HIV in sub-Saharan Africa

Nearly two thirds of all people living with HIV, almost 26 million, are in sub-Saharan Africa. In 2005 it is estimated that the region was home to 3.2 million new infections and 2.4 million AIDS deaths.[61]

In many African countries the epidemic has become generalised, with HIV spreading throughout the general population and not being confined to populations traditionally considered to be at higher risk, namely sex workers and their clients, men who have sex with men and injecting drug users. The growth of the epidemic in Sub-Saharan Africa is shown in Figure 2.

In most countries prevalence is now stable although it continues to rise in some countries, for example Madagascar and Swaziland, and is declining nationwide in Uganda and in smaller areas of several other countries. Often, the stabilization of prevalence is accounted for by rising death rates from AIDS whilst there is a continuing high rate of new infections. Even in Uganda where prevalence has fallen, the number of new infections remains high.[62]

Figure 2: AIDS epidemic in Sub-Saharan Africa 1990 - 2005

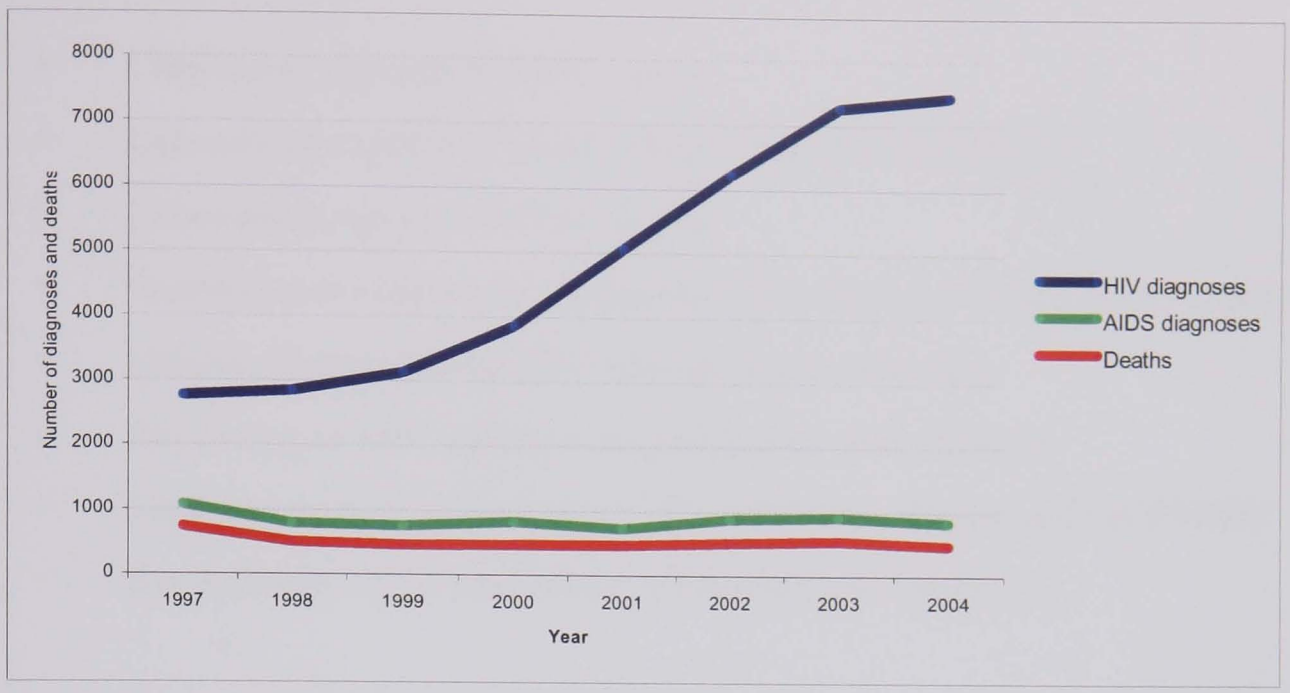
Data source: UNAIDS reports[61;62]

Heterosexual transmission is by far the most important mode of HIV transmission in sub-Saharan Africa. Although there has been recent debate about the role of unsafe medical injections in the spread of the epidemic, it is generally accepted that it is not the dominant explanation of the spread of the infection.[63;64]

2.3.3. Epidemiology of HIV in the UK

The number of newly diagnosed HIV infections in the UK continues to increase, most markedly since 2000; the annual total of 7275 diagnoses in 2004 was nearly double the 3851 diagnoses made in 2000.[9] By the end of 2004 an estimated 58,300 people were living with HIV, about a third of them unaware of their infection. Since the epidemic began in the UK in the early 1980s, 16,598 deaths are known to have occurred in HIV infected individuals.[9] However, although the number of people living with diagnosed HIV is rising each year, the numbers of AIDS diagnoses and deaths have fallen following the introduction of HAART in the mid-1990s. HIV and AIDS diagnoses and deaths 1997 - 2004 are shown in Figure 3.

Figure 3: HIV & AIDS diagnoses and deaths in HIV-infected individuals by year of occurrence in the United Kingdom, 1997-2004



Data source: HIV/AIDS reports.[11]

Note numbers will rise, especially for recent years, as further reports are received.

Sources of data

The Health Protection Agency's Centre for Infections receives reports on HIV infections from a number of sources (see Figure 4). HIV is a chronic infection with a long latent period so that multiple sources of surveillance information are required to understand the nature of the epidemic in the UK.[65] The main sources of information on newly diagnosed HIV/AIDS infection are voluntary case reporting of HIV/AIDS from laboratory reports of newly diagnosed HIV infections by microbiologists and HIV/AIDS diagnoses by clinicians.

In addition to reporting newly diagnosed HIV infections, other sources of data include an annual survey of all patients seen for HIV related treatment or care, and a number of unlinked anonymous surveys which test blood samples taken for other investigations, after they have been irreversibly unlinked from any patient identifiers.

Figure 4: Sources of UK surveillance data: HIV and AIDS[65]

- Clinicians' reports of AIDS cases
- Laboratory reports of newly diagnosed HIV infections
- Laboratory reports of CD4 counts
- Sentinel surveillance of diagnostic HIV testing ('denominator study')
- Unlinked anonymous HIV prevalence monitoring
- Reporting of HIV infection in pregnancy and children
- National survey of prevalent HIV infections diagnosed (SOPHID)
- Surveillance of TB and other AIDS indicator diseases

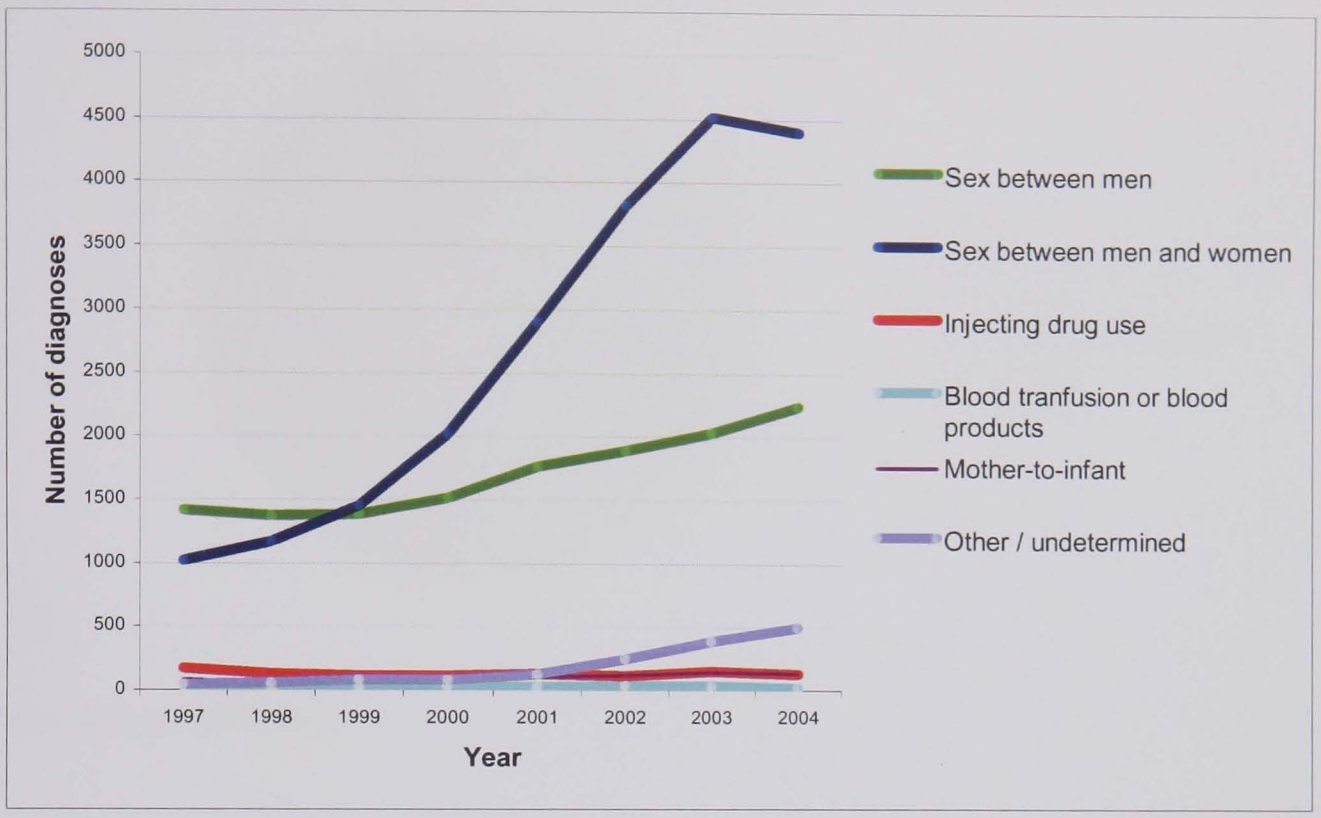
Exposure category

The major component of the rapid increase in recent years has been heterosexually acquired infections. Since 1999, the number of new diagnoses in heterosexuals has exceeded the number of new diagnoses of homo/bisexual men and by 2004 almost 60% of new diagnoses were in heterosexual men and women.[9;66] The major factor contributing to the increased numbers of HIV diagnoses in recent years has been increased diagnosis of infections acquired through heterosexual contact in HIV high prevalence areas, mainly Africa. Around 70% of the total HIV infections acquired through heterosexual contact were probably infected in Africa.[11] New HIV diagnoses by exposure category are shown in Figure 5.

HIV-infected persons seen for care

In the UK, 42,182 HIV-infected patients were seen for care during 2004, an 83% increase since 2000.[11] These increases reflect both the rise in numbers of new diagnoses and the decrease in HIV-related deaths since the introduction of more effective therapies.

Figure 5: HIV diagnoses by exposure category, United Kingdom: 1997-2004



Data source: HIV/AIDS reports.[11]

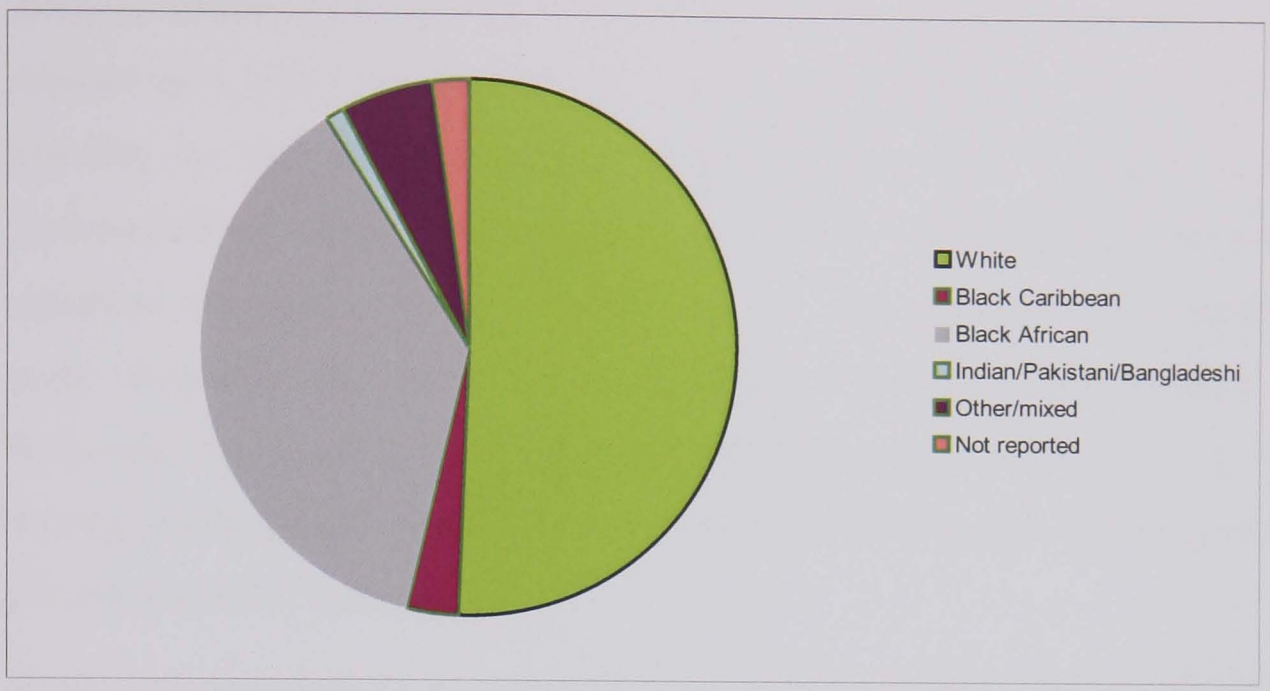
Note numbers will rise, especially for recent years, as further reports are received.

The largest proportion of HIV-infected individuals seen for care in 2004 were heterosexual men and women comprising 47% of the total and representing a 179% increase since 2000.[11] Of the 38,795 HIV- infected individuals seen for care in 2004 with ethnicity reported, 52% were white, 38% were black African and 3.1% were black Caribbean (see Figure 6), and of the heterosexuals alone 70% were black Africans.[9;67]

Place of residence

54% of HIV-infected individuals receiving care in 2004 were seen in London, down from 63% in 2000. The proportion of diagnosed individuals resident in London fell from 58% in 2000 to 49% in 2004. Corresponding increases have been seen in centres outside London.[9]

Figure 6: HIV-infected individuals seen for care by ethnic group, England, Wales & Northern Ireland: 2004



Data source: SOPHID[67]

Undiagnosed HIV infections

The Health Protection Agency estimates the number of undiagnosed HIV infections through combining data from the Unlinked Anonymous surveys with estimates of the size of the population derived from the National Survey of Sexual Attitudes and Lifestyles (Natsal 2000) and Census 2001 population statistics.[68] At the end of 2004 an estimated 58,300 adults aged 15-59 were living with HIV in the UK, of whom 34% were unaware of their infection.[9]

2.4. HIV testing

2.4.1. Background

Testing for HIV was introduced into the UK for general use in 1985 at a time when no effective treatment was available and fear and ignorance abounded. Merely being tested for HIV was perceived as stigmatising. Publicity in the gay press actively discouraged testing on the grounds that it could be used to discriminate against homosexual men and some health professionals opposed

testing on the grounds that testing positive could cause significant psychological distress whilst, clinically, there was little that could be offered.[69] Testing was viewed as a major intervention, which carried significant risks and uncertain benefits, so that people needed counselling in order to make an informed decision about whether to be tested.[70] Following the introduction of HAART the situation changed markedly with emphasis now placed on the importance of early diagnosis for access to monitoring, prophylaxis and treatment.[13;15;69;70] Reducing the number of undiagnosed HIV infections by promoting voluntary testing is a key focus of the Department of Health's National Strategy for Sexual Health and HIV in England.[15]

There is now a wide variety of screening tests available in the UK, the majority of which are designed to detect both HIV-1 and HIV-2. Traditionally these have relied upon a venous blood sample although there is now more than a decade of experience of using non-invasive tests based on saliva and urine samples and 'minimally-invasive' finger prick capillary blood spots. A carefully performed single assay which gives rise to a negative reaction is generally considered a sound basis for a negative report, making possible the same-day service provided in some settings. However, same-day reporting of a positive result is considered inappropriate because of the need for confirmatory testing. In the UK the standard approach is to employ at least two different tests following the initial reactive screening test, and most laboratories aim to report a result within five days.[71]

2.4.2. Antenatal HIV testing programme

Interventions during pregnancy and in the perinatal period can greatly reduce the risk of transmission of HIV from mother to child and a UK policy was introduced in 1992 to offer every pregnant woman voluntary confidential antenatal HIV testing wherever maternal HIV prevalence was high, and elsewhere to offer testing to women at increased risk.[72-74]

The recognised benefits of antenatal HIV testing increasingly led to calls for testing to be offered routinely to all women as part of antenatal care and in 1999 national targets and objectives were set that involved the offer of an HIV test to all pregnant women throughout England.[18;72;75;76] By increasing the uptake of antenatal HIV testing to 90%, it was anticipated that the number of children acquiring HIV infection from their mothers would be reduced by 80%.[77] The introduction of this opt-out approach, whereby women are routinely offered and recommended an HIV test (which they can refuse if they wish), has been shown to be effective in achieving substantial improvements in the proportion of maternal HIV infections diagnosed.[78] In August 2003 new standards were issued which reinforced screening for HIV as an integral part of antenatal care for all pregnant women in the UK and set out standards for communicating test results, making available specialist counselling and support, and referral for specialist HIV treatment.[79] Discussions with HIV-infected pregnant women are expected to cover the use of antiretroviral therapy and Caesarean section, early treatment and care for the child and decisions about breastfeeding.

The success of the antenatal HIV testing programme may have implications for HIV testing beyond the antenatal setting as attitudes among policy makers and health practitioners become more favourable to an opt-out approach to HIV testing.[80]

2.4.3. HIV exceptionalism

Since the earliest days of the epidemic, HIV/AIDS has been handled differently from other sexually transmitted or serious infectious diseases, a trend which has been termed 'HIV exceptionalism'.[16]

Attitudes to HIV testing, surveillance and contact investigation were influenced by the early history of the epidemic when the pathogenesis and natural history were poorly understood, treatment options were few and the disease appeared to be a focal epidemic spread by male-to-male sex and injecting drug use.

Concerns about abuses of civil rights brought together a coalition between the gay community, medical and health practitioners and proponents of civil liberties. A strong emphasis was placed upon clinical confidentiality and anonymised surveillance systems. The requirement for informed consent and counselling was particularly robust and some have claimed that the approach to the diagnosis of HIV was more akin to that of an incurable genetic disorder than an infectious disease.[81]

Exceptionalism initially had a limited impact on clinical care because available treatment options were limited and had a modest influence on prognosis. However, with the advent of more effective interventions there are personal and public health advantages to diagnosis. De Cock and others have long argued that attitudes and practice around HIV testing should be normalised, with the infection being treated more like other infectious diseases in which early diagnosis is essential for appropriate therapeutic and preventive measures.[18;19;82]

Pre-test discussion

The Department of Health introduced revised guidelines for HIV testing in 1996.[83] The guidelines confirmed the requirement for appropriate information to be given both about HIV transmission and the significance of the test result, and underlined that named testing for HIV requires informed consent. However, there was also an emphasis on encouraging HIV testing to be part of mainstream care, and a statement that any healthcare worker who has had appropriate training can carry out the discussion. Counselling, a concept that might have deterred some doctors from raising the subject of HIV with patients, was replaced with 'pre-test discussion' helping to demystify the process. Some have heralded this move as an opportunity to take HIV testing out of the realm of the specialist and into primary care and general medical settings where doctors use the skills involved in such discussion in their daily clinical practice.[75;84]

Informed consent

Under current guidelines, informed consent for testing must be obtained except in rare circumstances, for example an unconscious patient where testing would be in their immediate clinical interest. The patient must be given appropriate information about the test, including the advantages and disadvantages, and wherever possible be allowed appropriate time to consider and discuss them.[83;85] Verbal consent is preferred by the BMA Foundation for AIDS; signed consent is unnecessary and may itself act as a barrier to HIV testing.[70]

Although similar guidance exists in Belgium, a study based on 4807 HIV tests carried out by Belgian general practitioners found 102 tests (2.2%) were carried out without informed consent, replicating similar findings in the USA.[86;87]

Although some clinicians and others continue to emphasise the exceptional status of HIV, arguing in particular that the requirement for informed consent must be maintained, for at least some patients the issue of consent is not of great importance.[18;88] In a small study of patients at an Edinburgh hospital, 76% of patients said they would not have been upset if they had been tested for HIV without their consent, even though this would have breached ethical and professional guidelines.[89]

2.4.4. Confidentiality

It is generally recognised that there is a potential conflict between the principle of individual confidentiality and wider public health concerns. The General Medical Council (GMC) sets outs doctors' duties in respect of patient confidentiality; whilst confidentiality is recognised as important it is not enshrined as absolute.[90] In relation to HIV infection the GMC's guidance states *'you may disclose information to a known sexual contact of a patient with HIV where you have reason to think that the patient has not informed that person, and cannot be persuaded to do so'*.[85] The circulation of this guidance, which currently stands, gave rise to a flurry of discussion and complaint.[91;92]

The stigma and fear created by the disease, the lifestyles that have been associated with it and the potential for discrimination have put confidentiality to the forefront of HIV and AIDS care. The consequences for individuals of deliberate or accidental disclosure of their HIV status can be far reaching.[93]

It is widely recognised that fears about confidentiality may act as a deterrent to a person deciding to take an HIV test and there is anecdotal evidence to suggest that some people would prefer to attend a clinic separate from other services.[69] Studies in general practice settings suggest that there may be particular concerns about confidentiality in general practice, related to being known in the community or to reception staff having access to medical records, with patients believing that medical records at genitourinary medicine clinics are more secure.[94-96] Low levels of HIV testing in general practice settings have been associated with concerns relating to medical record disclosure to third parties, in particular for life insurance.[97] However, it is a myth that being tested for HIV by a GP rather than at a genitourinary medicine clinic causes insurance problems.[70] Applicants for life insurance who are HIV positive must disclose their HIV status regardless of whether their GP knows it; otherwise they invalidate the policy and could be prosecuted for attempted fraud. A change in policy by the Association of British Insurers (ABI) in 1994 means that insurers do not ask applicants whether they have been tested for HIV, only whether they are HIV positive. Joint Guidelines from the British Medical Association and ABI make it clear that doctors should not reveal information about whether a patient has taken an HIV test, had counselling in connection with such a test or received a negative test result, and insurance companies will not expect this information to be provided.[98]

There remains, however, considerable confusion over this issue with almost half of GP respondents in a questionnaire study wrongly believing that a negative test result will adversely affect insurance.[99] This incorrect belief, if conveyed to the patient, may well discourage uptake of the test.

2.4.5. Benefits of early testing

Cases still occur where people die of AIDS-related illness before HIV is diagnosed. Many people develop AIDS, which could have been prevented or delayed, and some die because they have not been tested for HIV early enough. Therapeutic advances leading to reductions in opportunistic infections and mortality from AIDS means that there are tangible benefits to be gained from an early diagnosis of HIV if appropriate interventions are initiated.[18]

The process of testing may also be an opportunity to promote behaviour change. The pre and post-test discussions provide an opportunity for one-to-one health education, which may bring about safer sexual or drug-taking behaviour if the test is negative. For those who test positive, there are opportunities to promote behaviour change to protect them from other sexually transmitted diseases and to protect their future sexual partners or those they share drug taking equipment with. However, a review of studies of behaviour change associated with HIV testing revealed inconsistent findings and concluded that there is insufficient evidence to claim that behaviour change results.[69] The authors suggested that this might be because the issue of safer sex is not fully addressed by clinicians even when HIV testing is carried out.

In Sweden there is an assumption that once a person infected with HIV becomes aware of their status they change their behaviour to protect their sexual partners.[100] Underpinning this apparent altruism is the statutory requirement that once someone is diagnosed as HIV positive they must tell their current and future partners of their infection and adopt safer sexual practices. The situation in the UK is less clearly defined although there have been a number of high profile legal cases which have found against HIV infected individuals who have not disclosed their infection status to their sexual partner.[101]

As yet, there is no substantial evidence in the UK that people infected with HIV are less likely to transmit the infection if they are aware of their status. Nor is there evidence that a person who has a negative test result will reduce their risk of being infected by modifying their behaviour. Promoting HIV testing must be

combined with identifying high risk behaviours and undertaking individual health promotion at every opportunity.[102]

However, the 'viral load' is a factor in the transmissibility of the infection. Thus if HIV testing has been undertaken and antiretroviral therapy has been initiated, there will be a reduction in the probability of transmission following viral load reduction, even if risk behaviour is not modified.[103]

2.4.6. Fears around HIV testing

Making the decision to have an HIV test is a stressful and sometimes traumatic experience and the period of waiting for the result can be particularly difficult. For some patients there may be anxiety and even depression associated with the fear of having contracted the infection and having infected others.[86] Most of the studies in the UK to date that have looked at the determinants of a person deciding to attend for HIV testing have focused on the experiences of gay and bisexual men who may be more sensitised to their risks of having contracted HIV. Amongst this group, reasons for testing can be divided into four main categories: an acknowledgement of past risk behaviour or having symptoms that could be HIV-related; a desire for reassurance and to relieve the anxiety associated with not knowing their HIV status; reasons related to present or future decision making regarding health, reproduction and sexual practices; or because they were advised to take the test by friends or health professionals.[69] Reasons for deciding not to test broadly relate to: anxiety about employment, insurance or mortgages; fears of not being able to cope with a positive result; concerns about confidentiality; implications for relationships and feeling that they have not been at risk.[69]

A qualitative study of HIV test recipients in Canada explored the testing experiences of a wider cross section of individuals and concluded that anxiety around taking the test is related to service and social context issues in addition to 'anxious apprehension' about test results.[104] Much anxiety relates to the stigma of the disease, with HIV infection meeting four criteria for stigma-evoking illnesses

in that it is terminal, it is widely perceived to be the responsibility of the one infected, it is contagious and often its effects are visible (see 'Stigma and disclosure' on page 49).[105]

There is little good quality research available on the factors which impact upon the decision to take an HIV test. A UK based study which aimed to identify predictors of testing intention in women identified a variety of socio-demographic factors, but the full decision making process and what disposes someone to decide to have an HIV test at a particular time needs further exploration.[69;106]

2.4.7. General practitioners and testing in primary care

From the early days of HIV infection, in areas of highest prevalence in the UK (particularly London and some other large cities), multidisciplinary teams came together to offer a wide range of primary and secondary care services based around the genitourinary medicine service, sometimes replicating those services more usually associated with general practice.[20] Genitourinary medicine clinics provide an open access referral service on a basis of strict confidentiality. Therefore, HIV/AIDS is unusual among serious and life threatening chronic diseases in that patients can access specialist hospital services directly, bypassing the traditional gate-keeping role of the GP. In addition, unlike other secondary care services, genitourinary medicine clinics are not routinely obliged to inform GPs of the attendance of their patient or the results of any investigation or treatment. Whilst some GPs saw advantage in not having to be involved with sexually transmitted infections, Singh et al. argue that such mutual withdrawal of the GP and the patient from each other limits the GP's ability to acquire sufficient relevant experience, and if sustained, may have consequences for the surveillance and identification of people with HIV infection.[20] GPs need to have the skills to identify signs, symptoms and risk factors for HIV in order to encourage more testing for HIV, resulting in earlier diagnosis.[107]

During the period 1990-2000 the number of voluntary HIV tests through seven sentinel laboratories (three in London and four outside of London) more than tripled.[17] Genitourinary medicine clinics reportedly accounted for nine times more first HIV tests than those generated by general practice. Although these laboratories were not randomly selected and cannot be assumed to reflect the situation with regard to HIV testing throughout England, they do account for 16% of HIV tests in the period and areas outside of London were well represented.

These findings contrast with the Lothian and Greater Glasgow regions of central Scotland, where 31% of all HIV tests between 1989 and 1993 were carried out by GPs.[108] In this Scottish setting GPs tended to be more knowledgeable about HIV than elsewhere in the United Kingdom. Primary care practitioners may therefore benefit from training which provides a good clinical understanding of HIV and confidence and ability in taking a history relevant to HIV risk. Together these enable a judgement to be made about the appropriateness of initiating a discussion about HIV testing.[109]

Missed opportunities for testing in general practice

GPs have traditionally been familiar with their practice population and their wide access to the population places them in a strong position to offer screening for sexually transmitted infections, such as chlamydia, within routine consultations.[110] Similar opportunities exist in relation to HIV although there is some evidence to suggest that opportunities are being missed. While possibly influenced by recall bias, a small retrospective study of women known to be infected with HIV revealed that 65% had seen their GP in the year prior to diagnosis but with few of these had the GP raised the subject of HIV.[111]

Of 3,400 named HIV tests carried out by a public health laboratory in an English, urban, non-metropolitan health authority, only 635 (18.1%) were initiated by GPs and of these 483 were for visa applications or prior to fertility treatment. Only 152 tests initiated in general practice (4.3% of the total) were recorded as having been for clinical rather than administrative purposes.[112]

It has been argued that without more widespread testing by GPs the missed prevention opportunities could be considered negligent practice.[18] All GPs should be encouraged to offer the test without the need to refer to specialist services.[113] Indeed, the BMA Foundation for AIDS claims that referral to a genitourinary medicine clinic for HIV testing is itself an unnecessary barrier.[70]

The National Strategy for Sexual Health and HIV underlines that HIV testing has always been possible in primary care whilst recognising that in practice its availability is variable.[15] One of the key objectives of the Strategy is to increase the offer of testing for HIV and to reduce the number of undiagnosed infections thereby ensuring earlier access to treatment and limiting spread of the virus. HIV testing and counselling has therefore been designated as a service that should be available in every general practice setting.

Knowledge and attitudes amongst GPs

Early studies into the GP's role in HIV infection revealed a degree of reluctance among patients to use GP services.[96;114;115] Certain patient groups, especially gay men, perceived GPs to be prejudiced and ignorant of their lifestyles as well as their clinical condition.[94;116] These perceptions of negative GP attitudes were, in part, borne out by an early study showing that almost one in six would consider refusing to treat infected patients, although younger doctors had less hostile reactions and better understanding.[117]

More recently a small study of 106 HIV positive women found that the majority were willing to disclose their status to a GP. Of the 81% registered with a GP, 83% had disclosed their HIV status. Of the women not registered or who had not disclosed their status fears over confidentiality and being unsure of the GP's reaction were the main concerns.[115]

An in-depth interview study with 20 HIV positive individuals found that negative expectations of GPs may not be based on actual experience.[112] The researchers found that although actual experiences of general practice were predominantly positive, negative perceptions of GPs with regard to prejudice or

hostility persisted, with patients circulating an informal list of so-called 'safe' GPs.

It may be that the anxieties of GPs themselves are part of the problem. Amongst a self selected group of GPs attending a study day on sexually transmitted diseases (and therefore likely to be more knowledgeable and interested in sexual health than their colleagues) there were high levels of anxiety around raising the subject of HIV with certain high risk groups.[118] Patients may interpret this lack of confidence as disinterest or lack of support.

The knowledge and experience of GPs in HIV care is variable. A survey of GPs working in four high prevalence South and West London Primary Care Groups in 2000 found that 96 of the 117 respondents (82%) had some involvement with HIV positive patients in the previous 12 months, although only 16 (14%) considered themselves to have 'quite a bit' of experience of patient care.[119] The relatively high level of involvement amongst this group of GPs may reflect the study setting (a large number of HIV positive patients are located in West London), with GPs outside of London having different experiences. However, even in this high prevalence area, only a small minority of GPs had attended recent HIV training events, and a large majority indicated a desire to increase their knowledge.

The patient's perception of a lack of knowledge and clinical expertise in relation to HIV may act as a barrier to a patient involving the GP in care relating to HIV.[21;94;96] Petchey's interview study of 20 HIV positive individuals found that most participants felt that there was limited knowledge and clinical expertise relating to HIV within general practice.[112]

Perceived lack of knowledge amongst GPs may not always be the most important barrier to testing. A questionnaire survey of people attending a same day testing clinic for an HIV test found that less than one sixth had discussed HIV testing with their GP even though the majority had visited their GP in the preceding 6 months. Although possibly limited by recall and selection bias, it is interesting to note that this study found that lack of GP knowledge was not cited

as a prominent reason for the lack of discussion, with the majority feeling that their choice primarily related to wanting a 'same day result'.[95]

The knowledge of some GPs in relation to risk of infection and preventing virus transmission, together with continuing confusion over insurance implications suggests the need for strengthening the training available to GPs.[97;99;120;121] Although some GPs are suitably knowledgeable and confident about raising the subject of HIV with their patients and delivering appropriate advice and care, high levels of anxiety remain amongst some GPs and training is required in order to take full advantage of the potential for general practice in tackling HIV.[75;109;118] Indeed, some propose a model of care that would manage stable HIV infection as any other chronic condition, with GPs taking the lead not only in health promotion and identification of disease but also in community based on-going care.[20]

Madge and Singh claim that the scientific strides which have been made with HIV infection demand that GPs come off the 'testing-fence' and treat HIV as any other serious infection recognising that its course can be modified in the light of current interventions.[75]

Time availability

A potential barrier to GPs increasing their involvement in the area of HIV infection is the perceived pressure of time.[21] The move away from counselling towards the Department of Health's recommended pre-test discussion means that HIV testing need not be too time-consuming to be done within general practice.[83;95] Even before the introduction of the new recommendations, thorough pre-test counselling took no more than 10-15 minutes with the average time taken by midwives being only 7 minutes.[69;122]

2.5. HIV in UK African Communities

2.5.1. Demographic characteristics of the UK African community

At the time of the 2001 census black Africans accounted for 0.9% of the population of England and 78% lived in London.[123] Identification of the black African population can be difficult, despite attempts in the 2001 census to include a more comprehensive ethnicity question than that used in 1991. There are thought to be particular issues for younger black African people who may not necessarily identify themselves as such, and members of some African groups, in particular those from Somalia, may consider themselves to have more in common with Arabic cultures. In addition, those whose immigration status is unclear or insecure, especially those whose application for asylum or leave to remain has been turned down, may be wary of official contact. Furthermore, asylum seekers and refugees often live in temporary or shared accommodation or are highly mobile, and may have limited English, all of which reduce response rates.[124] Thus it has been claimed that that black Africans are a 'hidden population' that may be difficult to engage in HIV research and prevention interventions.[125]

The African population is heterogeneous, comprising people with varied historical experiences, both at the individual and group level, and with complex ethnic identities and cultures. The cultural, economic and political differences that exist within and between African countries have been shown to persist in communities in the UK.[126] There is great diversity in country of birth, settlement patterns, patterns of migration and travel to the UK, as well as ethnic, sub-ethnic and linguistic groupings.[125] The majority of Africans in the UK are traditionally of West African origin although increased political instability since the 1970s has meant an increase in asylum seekers from Somalia, Ethiopia, Eritrea, Uganda and more recently Zimbabwe.[127]

The African population tends to be younger than the UK population as a whole, with over 80% being under the age of 40, the majority being single and a higher

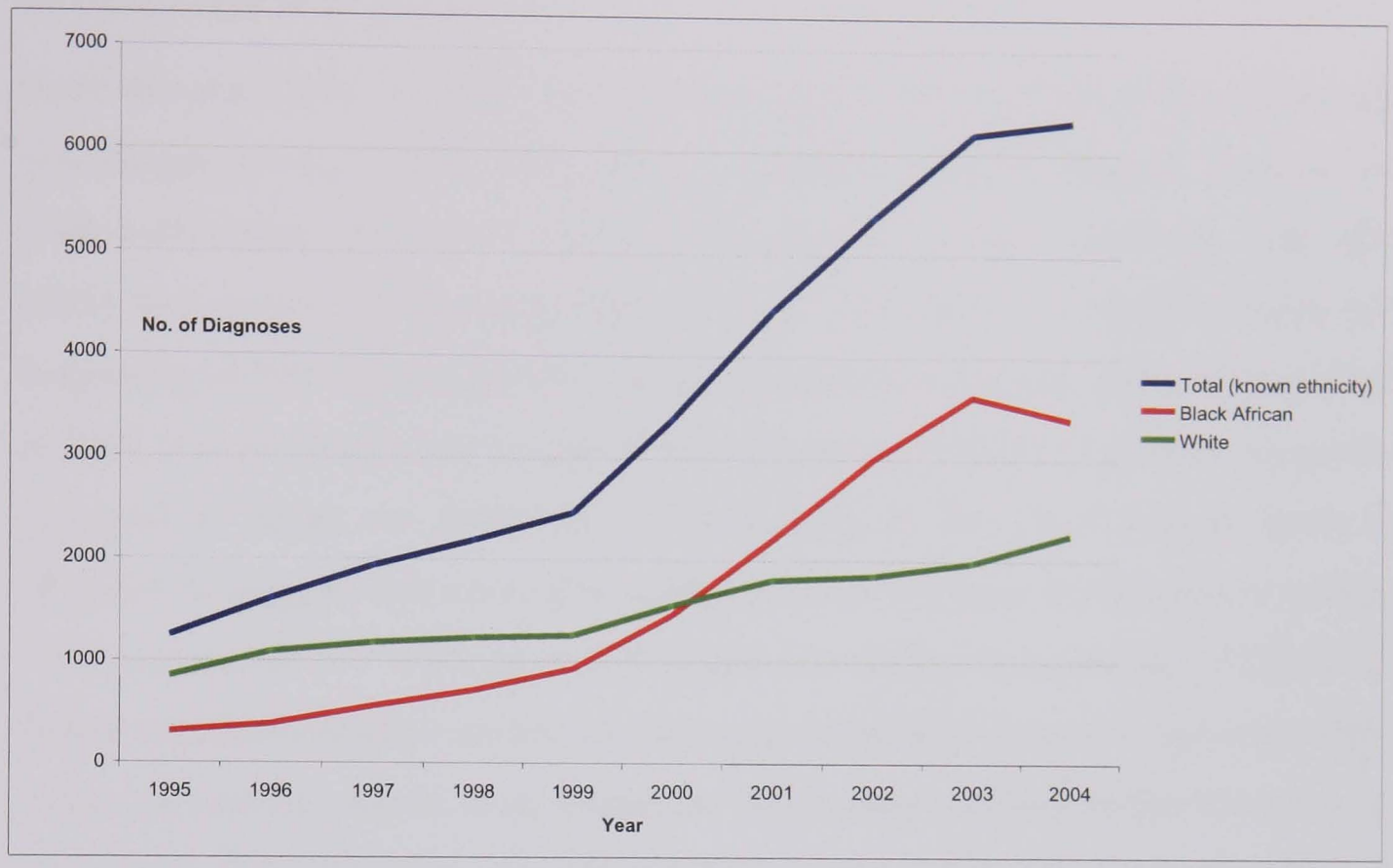
proportion of people having a first university degree or higher.[25] It is also known to include a high proportion of students living in rented flats, and to have a higher proportion of people suffering overcrowding and inadequate amenities than most other ethnic groups.[127]

A greater proportion of African households consist of a single person than any other ethnic group, possibly reflecting a pattern of migration in which only part of the family comes to the UK. Many Africans living in England experience social problems associated with high levels of unemployment, low incomes, poor housing, high crime environments, poor health and family breakdown.[128]

2.5.2. Epidemiology of HIV in UK African communities

The UK African population is disproportionately affected by HIV and a substantial component of the increasing number of HIV infections in the UK is accounted for by black Africans (see 'Epidemiology of HIV in the UK' on page 15). By combining data from the 2001 Census with data from the SOPHID survey it is estimated that 4.4% of black Africans aged 16-44 were living with diagnosed HIV infection in 2004 compared with 0.07% of the white population.[9] Figure 7 shows the number of diagnosed HIV infections by ethnicity.

Figure 7: HIV infected individuals of known ethnicity by year of diagnosis and ethnicity. United Kingdom data 1995-2004



Data source: Health Protection Agency Quarterly Surveillance Tables[129]

Geographical distribution in the UK

The majority of black Africans with HIV infection in the UK live in London although the proportion outside the capital has been rising.[9] There are increasing numbers of 'new' African communities who carry a heavy burden of HIV and AIDS including students, nurses, and asylum seekers. In recent years these communities have increasingly settled or been 'dispersed' outside of London (see page 39), with the most marked increase in the rate of new HIV diagnoses in heterosexual people being seen outside of the capital.[23;24]

Time since arrival in the UK

Information regarding the length of time spent in the UK before a diagnosis of infection with HIV is often incomplete. In a large study involving the retrospective examination of the case notes of 1056 African patients this information was only present in 368 (35%) of cases.[130] For this group, the median

length of time spent in the UK before being diagnosed HIV positive was 12 months (range 0-261 months).

Since the year 2000, data have been collected on year of arrival in the UK for all new diagnoses where HIV infection was probably acquired abroad. Even so, of 1448 individuals infected in Africa and diagnosed in the year 2000, only 627 (43%) had year of arrival recorded. Of these, 366 (58%) had arrived since the beginning of 1999. Although the year of arrival, where known, ranged from 1963 to 2000, it seems that many people newly diagnosed with HIV infection probably acquired in Africa are relatively recent arrivals to the UK.[10] Indeed, there is evidence to suggest that up to 40% of HIV positive Africans are diagnosed within 1 year of arrival[131;132] with up to 25% diagnosed within 6 months (see Table 1).[132] Based on a retrospective review of African patients attending two specialist HIV clinics in London, Burns et al. found the mean time resident in the UK prior to diagnosed HIV infection was 36 months, noting that this time period had remained constant between the two comparison periods 1982 to 1995 and 1998 to 1999.[13]

Table 1: Number of months in UK before diagnosis adapted from O'Farrell et al[132]

No .of months in UK until HIV/AIDS diagnosis	**HIV diagnosis n=77 (%)**	**AIDS diagnosis n=76 (%)**	**Patients diagnosed with HIV/AIDS at the same time n=52**
0-6	19 (25)	19 (25)	17
7-12	11 (14)	7 (9)	7
13-18	6 (8)	6 (8)	5
19-24	9 (12)	5 (7)	4
25-48	22 (29)	26 (34)	14
49-72	5 (6)	8 (11)	3
>72	5 (6)	5 (7)	2

Gender difference

The female to male sex ratio amongst black Africans diagnosed with HIV infection in the UK is higher than in other ethnic groups. Of the new diagnoses of HIV in black Africans made in the year 2004, 64% were in females.[133] A greater proportion of the HIV infections in black African women are made in pregnancy

indicating the potential for vertical transmission of infection.[10] The increase in antenatal testing may partly account for the sex imbalance but it is likely also to reflect the different HIV rates by gender in sub-Saharan Africa.[134]

Undiagnosed HIV infection

At the end of 2004, 60% of heterosexuals living with HIV were African born, and it is estimated that around a third were undiagnosed.[9;11] Prevalence of previously undiagnosed HIV infection for those born in sub-Saharan Africa in 2004 was 3.8% compared with 0.2% among heterosexuals born in the UK. Outside London the prevalence of previously undiagnosed HIV infection for those born in sub-Saharan Africa was 7.1%, which may reflect the dispersal of more recent migrant populations to areas outside London.[9] Although less than 10% of newly diagnosed heterosexually acquired HIV infections are thought to be attributable to heterosexual intercourse within the UK, the number is rising and is likely to increase further particularly among African communities.[135] One of the key aims of the National Strategy for HIV and Sexual Health is to reduce undiagnosed HIV thereby facilitating earlier access to treatment and limiting further transmission.[15] In particular, the implementation plan recognises the importance of targeted work with African communities in the UK in order to reduce the number of undiagnosed infections.[136]

2.5.3. Presentation and progression of HIV infection in UK African communities

Closely linked to the number of undiagnosed infections is the stage of disease at time of first diagnosis. It is commonly recognised that African adults in the UK generally present at a more advanced stage of disease progression than non-Africans, and with lower CD4 counts at diagnosis, despite the advent of Highly Active Antiretroviral Therapy (HAART).[9;13;125;128;137;138] Sometimes HIV diagnoses are made so late in the course of disease progression that treatment has no time to avert complications or death.[139]

Since the introduction of HAART, HIV wards in many London hospitals have been closed due to a fall in the need for in-patient care as a result of the effectiveness of these drugs. In hospitals where there are many African patients this trend is less noticeable, and is likely to reflect delayed presentation and the reduced effectiveness of HAART when initiated late in the disease at a time when the immune system may already be seriously compromised.[140]

A retrospective study of case notes of all HIV infected Africans attending 11 treatment centres in London between 1982 and 1995, and a comparison group of HIV infected non-Africans (1056 Africans and 992 non-Africans), found that the median CD4 lymphocyte count at presentation was significantly lower in African ($238x10^6$ cells/l) than in non-African ($271x10^6$ cells/l) patients ($P<0.001$).[130] The study involved almost half of Africans with HIV reported in the UK and almost one third of those reported with AIDS.

Other studies have similarly found that HIV infected people of sub-Saharan origin present with late disease.[10;131;141;142] Elsewhere in Europe, the large Swiss HIV Cohort Study has enabled nearly 12,000 HIV infected individuals to be followed prospectively, with a similar finding of later presentation in migrants from sub-Saharan Africa than other HIV infected groups.[53]

In addition to presentation with lower CD4 counts, a considerable proportion of African patients present with an AIDS defining illness at the time of first positive HIV test result. A small study of 86 African patients attending four HIV specialist centres in London found that the diagnosis of AIDS was coincident with a first positive HIV test result in 61%.[132] A larger and more recent study confirms that significantly more African patients had an AIDS-defining illness within one month of their HIV diagnosis than non-Africans, even in the era of HAART. Indeed, comparison over time shows that African patients in London were more likely to have AIDS at presentation in 1998-1999 than in 1982-1995.[13]

A number of studies have shown that considerable numbers of HIV positive Africans were only diagnosed with HIV infection following admission to hospital, up to 70% in some reports.[132;137;143] Anderson and Doyal found that

more than 70% of the 62 African women in a questionnaire study were diagnosed as a result of their own ill health, or the ill health or death of a partner.[144]

Disease progression

Few reliable studies have examined the natural history of HIV infection in Africa. Cohorts of individuals where there is documented evidence of positive and negative HIV tests are rare, making estimates of dates of seroconversion unreliable. There is however a widespread impression that progression of disease in sub-Saharan Africa is more rapid than in the industrialised world. One well conducted study in Uganda, which created a clinical cohort of prevalent cases by using annual HIV serosurveys in a population of 4500 adults, found that the median time from seroconversion to AIDS was 9.4 years and from AIDS to death, 9.2 months.[145] The authors concluded the results show some similarities to disease progression in industrialised countries before the introduction of potent antiretroviral therapy.

An important question is whether in industrialised countries such as the UK, differences exist between rates of progression in Africans and non-Africans, and if so whether this is due to host, viral or mainly environmental factors. There is some evidence to suggest that the survival experience of HIV infected African migrants who reside in London is more similar to groups of HIV infected individuals who were born in the UK than to those living in Africa.[141] A retrospective cohort study of 1056 African and 992 non Africans seen in 11 large HIV/AIDS units in London between 1982 and 1985, concluded that after adjusting for different stage of presentation, age, sex and year of HIV diagnosis, there was no statistical evidence of an increased risk of progression to AIDS or from AIDS to death, attributable to African ethnicity.[146]

In the UK, the spectrum of initial AIDS-defining illnesses is different in HIV infected Africans compared to non-Africans, with pulmonary TB playing a particularly important role.[10;130;131;146;147]

However, despite later presentation, with lower CD4 counts, more advanced clinical disease and different initial AIDS-indicator diseases, Africans have been shown to have similar CD4 counts to non-Africans when presenting with specific AIDS-indicator diseases. Diseases associated with profound immunodeficiency occur more commonly among HIV-infected Africans in London than in sub-Saharan Africa and it has been claimed that differences in environmental exposures, such as to acute bacterial infections, and the lack of access to treatment may be important in explaining the apparent difference in outcome for HIV infected persons in Africa compared to the UK.[130]

2.5.4. Culture, beliefs and the experience of being a migrant

Immigration and asylum issues

Issues related to immigration status are a frequently perceived barrier to accessing HIV testing and care. In the UK, free primary and secondary care is currently limited to people fulfilling certain conditions (Figure 8). Asylum seekers are eligible to treatment only if they have made an application to remain in the UK. The exceptions to this rule are emergency care, treatment of sexually transmitted infections (excluding HIV) and other conditions that threaten public health.[148] Outside of these eligible groups, free treatment for HIV/AIDS is limited to a diagnostic HIV test and associated counselling. The eligibility criteria are often unclear to patients and impacts on the decision to access medical services, as they are reluctant to present themselves to clinic until ill health makes it unavoidable.

Some asylum seekers are afraid that an HIV test or going for a test might affect their rights to stay in the country and therefore choose not to confront such an issue.[149] In addition, some fear that even if they were able to start treatment in the UK they would most likely not have access to antiretroviral treatment if returned to Africa.[140]

Figure 8: Eligibility for NHS treatment

Eligibility for full NHS treatment

Eligible

- Anyone who has been living legally in the United Kingdom for 12 months
- Permanent residents
- Students in the UK for > 6 months
- Refugees or asylum seekers who have made an application to remain in the UK
- People detained by the immigration authorities
- People from countries with a reciprocal agreement

Not eligible

- Students on courses for < 6 months
- Those who have not yet submitted an asylum or refugee application to the home office
- Those who have had an application turned down
- Illegal immigrants

Adapted from Pollard and Savulescu[150]

In April 2000, the UK National Asylum Support Service started a policy of 'dispersing' asylum seekers from London and southeast England to alternative parts of the United Kingdom following the introduction of the Immigration and Asylum Act (1999).[151]

Even in the context of universal health care, migrants and ethnic minorities often face strong barriers to accessing HIV/AIDS prevention and care services.[152] Dispersal may have an additional impact by forcing people away from the capital where African communities have traditionally been focused, and where community organisations are likely to be more mature in their development and the services they are therefore able to offer. Health and social care providers outside of the capital report lack of cultural competency in addressing the HIV prevention and other needs of this emerging population.[125]

Asylum seekers might only receive 48 hours notice of dispersal under the current system. If they decline they face immediate cessation of income, housing and legal support. Where an asylum seeker is HIV positive, this could compromise

patient care as well as leading to HIV resistance and onward transmission of HIV infection.[153] A national survey of doctors working in genitourinary medicine found that most had experience of dispersal of HIV positive asylum seekers against medical advice.[154]

Uncertainty about immigration status is a major source of stress for many Africans living in the UK with HIV.[125] In a questionnaire based study of 435 HIV-infected African participants (Project Nasah), more that half cited dealing with the Immigration Service as a major problem.[137] The authors suggest that uncertain immigration status impacts upon many other aspects of life, including access to money via work or benefits and in turn access to reasonable housing.[137]

In addition, many African people face a media that appears broadly hostile to their residence in the UK, with growing calls to test migrants and asylum seekers at the point of entry, and to restrict access into the country or to medical services once here.[137;155] In response to these calls, the All-Party Parliamentary Group on AIDS established an enquiry into the impact of the UK nationality and immigration system on people living with HIV. It recommended that the Government should reaffirm its commitment to the UNAIDS guidelines against mandatory testing upon entry for HIV.[153]

The Institute of Policy Studies also considered calls from a number of quarters for pre-entry screening for both TB and HIV for all permanent migrants to the UK and compulsory testing (and detention) on-entry for all asylum seekers. The report found that such screening was likely to be ineffective and costly, and might have negative consequences, for example causing those who know they are infected to 'go underground' merely increasing the risk of the disease spreading.[156]

Culture and identity

Many Africans have only recently migrated to the UK and hold specific beliefs and practices from their country of birth. In addition to the degree of

acculturation, factors affecting beliefs and practices include gender, ethnic origin (tribal group) and religion.[125;128]

One of the few available sources of information on beliefs and lifestyles of African communities is a recent qualitative study conducted among 44 representatives of organisations working with people from four black African communities: Ghanaian, Nigerian, Somali and Ugandan.[124] The authors conclude that migration impacts African identity differentially within different communities and across age groups. Some African migrants come to the UK because of a strong sense of identity with British culture and values, whilst for more recent migrants there may have been little choice about where they have ended up living. Therefore, some communities include those who seek to embrace the culture they are now living in, whilst others seek to retain their cultural identity. For some, being a minority ethnic group has led to a stronger desire to retain an African identity than they might have felt if they had remained in their home country. Generational differences appear to exist, with older people seeking to maintain and promote traditional values, whilst younger people see themselves as having dual or conflicting identities.

The same study found a high level of agreement that the experience of migration impacted the traditional roles and status of men and women in African communities. Traditionally men are seen as the providers, often associated with a balance of power which is in the man's favour, whilst migrant African men felt that women were more assertive and less tolerant of the traditional behaviour of the men. However, the imbalance of power was to some extent still present. For example, organisations working with the Ugandan community reported that men could be domineering and objected to women attending workshops or meetings, and it was also apparent that amongst newer arrivals gender inequalities and divisions were more pronounced. Thus in some newer Ugandan communities, as opposed to the more established Nigerian and Ghanaian communities, women did not socialise in public places, the power balance in the home was in favour of men, women might not be free to talk about sex openly,

and some respondents reported the expectation upon women to be shy, provide care and put the needs of their families before themselves, leading to a degree of isolation in the community.[124]

Most African women and men in the UK seek marriage and about two-thirds are married by their mid-thirties. For the majority, their marriage partners are other African men or women, although this finding is based on data obtained before more recent increases in refugees from Africa in the early 1990s.[125] For some, marriage partners and even children may be living abroad in an African country with the UK based parent sending money to their country of origin to support children and their carers.[124]

For many African women motherhood is a source of identity and there are sometimes profound economic and social consequences within African cultures for women who do not conceive. For African women living with HIV in the UK, reluctance to give birth to a child who may be HIV positive, together with fear that sexual activity might put the potential father at risk of infection, may be difficult to reconcile with the importance of motherhood.[157] The Padare Project assessed the pregnancy intentions and outcomes of 214 HIV infected Africans living in London and found that 4% of women had become pregnant since the time of diagnosis.[158]

Many Africans living in the UK hold religious and spiritual beliefs; the church plays an important role both as a place of worship and as a focus for social, cultural and educational activities.[159] For many, traditional African religions are followed alongside Christianity, or for a minority of people from sub-Saharan Africa, a Muslim faith.[124] To varying degrees these beliefs impact upon diagnosis, treatment and response to living with HIV.[158] One study reported that over 90% of the 62 HIV-infected African women interviewed described their religious faith as a major source of support in coping with the difficulties they face.[144] Some Africans believe that spiritual forces hold ultimate control of the future and view prayer as a possible route to healing. Religion and medicine are often seen as complementary, although reliance on medicine is sometimes seen as reflecting

inadequate faith, with some religious groups actively discouraging the taking of medication in favour of using the power of prayer.[140;160]

However, despite the importance of religion and church attendance in the lives of Africans, there is often a reluctance to discuss HIV in a setting that is sometimes regarded as a threatening space, where there is fear of lack of confidentiality and rejection by other members of the congregation.[157;161]

Health and health beliefs

Those who migrate from their county of birth are generally healthier than those who do not but this 'healthy migrant effect' tends to wear off with time. Social exclusion, racism and social disadvantage are all part of the picture when considering the health of migrant communities.[162;163]

In 2004, The Health Survey for England included black Africans, in its focus on the health of ethnic minorities, for the first time.[164] However, little remains known about the health of the black African population in England, their use of health services and how their health beliefs, environments and lifestyles may influence their health.[152;164] Elam et al. carried out in-depth interviews with black African sub-groups from Uganda, Nigeria and Somalia to explore the feasibility of including a population boost for the 2003 Health Survey, concluding that these groups attach high importance to maintaining mental and spiritual well-being.[127] Spiritual practices included the drinking of holy water and the reading of, or wearing extracts of, the Koran. The use of traditional African medicines by people known to be infected with HIV (for example extracts of leaves and barks) may be limited by lack of availability although there are reports of such remedies being sent from Africa.[127;140;165]

Sexual behaviour and sexual health

There has been limited research carried out in the British context exploring sexual health and ethnicity. Most is quantitative in nature and is limited by data availability. Although NHS data now includes ethnicity, it does not routinely record socio-economic status, country of origin, period since migration and

generation of migration. It has been claimed that researchers have too often used the label 'black African' in ways that obscure the heterogeneity of this group, with little attention to important variables such as nationality, ethnicity, religion, socio-economic status, gender, age and time since migration.[28]

Many culturally prescribed practices influence sexual health and the risk of sexually transmitted infection. These include the use of vaginal herbs, circumcision, vaginal douching and concurrency and may be targets for behavioural modification for risk reduction.[166]

The Mayisha study, a community-based sexual behaviour survey amongst Kenyan, Congolese, Ugandan, Zambian and Zimbabwean communities in Camden and Islington, found that the use of herbs as vaginal drying agents ('dry sex') were used across all African communities with 15% of men and 14% of women reporting the practice of dry sex in the UK.[167] This is contrary to the belief that dry sex is only practised by certain tribes in Africa and suggests that sexual practices in the UK might become more heterogeneous through heterosexual mixing of people from different communities. This has particular implications for HIV transmission as it has been argued that the use of vaginal drying agents is associated with an increased risk of transmission.[168]

The first wholly qualitative study of sexual behaviours amongst ethnic minorities in Britain, conducted by Elam et al., found that there are important differences in the ways that individuals make sexual decisions, which are influenced by the power relations and cultural norms prevalent within their own communities.[169] The sub population of Africans in the study was fairly small and included only Ugandans and Nigerians. Even so, it was clear that there were important regional and tribal differences within these broad country categories, while religious conviction, family structures, gender roles, behavioural norms and 'moral' beliefs and level of acculturation all affected sexual lifestyle.

African respondents often reported good knowledge of HIV but inconsistent safe sex behaviours, often believing that risk could be avoided by careful partner choice and that it was easy to identify potential partners who carry a high risk of

being infected with HIV. Where multiple sexual relationships formed the sexual lifestyle, lapses in condom use were justified by the choice of safe, 'clean' partners. Reducing the number of partners was not considered a safer sex practice, but the careful choice of a partner was. Among African men there was a dislike of condoms and where condoms were used in a relationship, there was a reluctance to use them in the long term.[169] Kesby argues that socio-cultural mores may mean that African men often have multiple sexual partners whilst African women seem to want stable monogamous relationships, preferring to ignore the fact that infidelity is relatively common and not wishing to be reminded that their partner may be unfaithful by having a frank discussion about condom use.[28] Engaging in unsafe sex is often understood as a strong demonstration of trust and ignoring health risks may be seen as preferable to jeopardising a partner's trust by discussing safety or questioning fidelity. This might be especially the case where multiple partnering is common but not publicly acknowledged and where men and women have different attitudes to fidelity.[28]

The Padare project, which explored the attitudes and behaviours of 214 HIV positive African men and women living in London, found that large numbers engaged in sexual activity that was of significant risk to themselves and their sexual partners; 27% of men and 35% of women reported unprotected sexual intercourse with their most recent sexual partner.[158] Although lower than seen amongst a community based sample of Africans of unknown HIV status, this represents a level of risk behaviour that places many of them and their sexual partners at risk of HIV.[158;167]

The existence of a continent-wide 'African sexuality' which is particularly vulnerable to HIV has been proposed. Caldwell claims that sexual relations are not regarded as sinful or subject to moral control and that sex in Africa is a worldly activity which always has a potentially commercial aspect.[170] Heald claims that whilst sex is an everyday element of life, it is also a complex sacred phenomenon and a powerful force, and that African people have traditionally

been preoccupied with sexual morality, although this is based on notions of 'right and wrong mixing' rather than fidelity.[171]

Others argue that multiple phenomena make sub-Saharan Africa a high-risk context in relation to sex, and that culturally specific high-risk behaviours must be seen as products of historical and geographical processes, for example the economic crisis in Zimbabwe and labour migration in South Africa.[28;172] Rapid HIV transmission in Africa is rooted in historically produced poverty, chronic ill health, unequal gender relations and particular sexual behaviours that are regionally specific. Many questions remain regarding the extent to which these factors persist among African people after migration to Britain.

Further questions are raised about the connections between the British and African contexts by a recent quantitative study which interviewed 756 African migrants in London regarding return to their country of origin.[173] More than 40% had returned to Africa within the preceding five years and over a third of these (40% of men and 21% of women) had acquired a new sexual partner whilst abroad. Re-entry into the high-risk context of Africa has implications for the importation of HIV into the UK. It is not clear however, to what extent engagement in new sexual partnerships on return to the country of origin is consistent with the practices in that setting, nor whether the visits act to reinforce or re-establish pre-migration sexual practices. However, the relatively high socio-economic status of people visiting from the UK could enable them to enter or re-enter sexual networks where transactional sex is commonplace.[173]

Multiple relationships and sexual mixing

Elam's qualitative study suggests that serial monogamy is one of the most consistent features of the sexual lifestyles of Nigerian and Ugandan women living in the UK, with concurrent or one-off sexual contacts more common amongst men.[169] The authors propose that this contrast is related to different behavioural norms for men; from an early age African men are encouraged to have sex in a way that the women are not, with sex considered a natural activity, not requiring a relationship or emotional ties in order to take place. Casual sex is

not regarded as morally wrong, rather a natural expression and activity of youth. The implications of this are important, as concurrency in relationships has been associated with an exponential increase in the transmission of HIV.[174]

The nature of the relationships entered into by attendees at a sexually transmitted diseases clinic in London between 1992 and 1995 was studied to assess the degree of sexual mixing amongst heterosexual subgroups based on country of birth.[12] In the population of 15,878 attendees, when country of birth of parents (family origin) was taken into account it was found that sexual mixing was highly assortative (like-with-like). The authors postulate that this could help to explain the low spread of heterosexual HIV infection within the indigenous UK population to date.

2.5.5. Knowledge, beliefs and living with HIV

Supernatural beliefs about the causation of HIV/AIDS are widespread in many parts of Africa and include beliefs that sickness might be caused by witchcraft, ancestors' anger and pollution through breaking taboos. Traditional healers and witchdoctors are often considered best placed to overcome the spiritual forces causing disease.[175;176] Other theories include a belief that the epidemic is a racist conspiracy to discredit Africa or a means for international agencies to control Africans through the introduction of condoms, or even a means for conservative religious groups to control 'promiscuity'.[177] Recently, there have also been claims that unsafe injections, that is using equipment that is reused without first being sterilised, are a major if not the main mode of HIV transmission in sub-Saharan Africa, although this theory runs counter to the widely held orthodox epidemiological interpretation about the lead role of sexual transmission in spread of the disease.[64;178-180]

Understanding the African context is important in understanding the knowledge and attitudes to HIV of Africans now living in the UK. Moving to a new country does not immediately change the long held cultural beliefs or alter the knowledge base. Many have witnessed the catastrophic consequences of HIV in

their own families and communities in a setting where few have access to treatment and survival times are much shorter. Attitudes towards HIV, particularly fear of death from HIV related disease, may be coloured by these experiences.[144;160;181]

Many Africans living in the UK face their diagnosis of HIV infection in the context of stigma and secrecy, financial insecurity and uncertainty about their immigration status. Financial and housing problems are up to ten times more prevalent among African people with HIV than white British people living with HIV.[137;140] For some there will be associated physical limitations imposed by ill health as a result of HIV disease itself particularly as later diagnosis in Africans inevitably means more advanced disease at presentation (see page 36).

For many Africans, living with HIV is on a background of at least one profoundly traumatic life event.[182] Rape, murder of a partner and family members and various other forms of persecution were relatively common experiences amongst HIV positive African women in London.[160;183]

It is not surprising on this background that mental health problems are common, particularly anxiety and depression.[137;183] However, although African patients with HIV have been shown to suffer from more severe psychiatric morbidity, they may be up to three times less likely to be referred for specialist mental health care.[184]

Stigma and disclosure

There is an extensive literature on stigma in relation to HIV and AIDS, much of it taking as its starting point the now classic work of Goffman, defining stigma as 'an attribute that is significantly discrediting' which serves to reduce the person who possesses it in the eyes of society.[185] Drawing on research amongst people with mental illness, physical deformities or socially 'deviant' behaviours, Goffman argued that stigmatised individuals have a 'spoiled identity' and are subjected to the judgement of others and often blamed for their misfortune. The debate in relation to HIV has moved on considerably in recent years to consider

the context of culture and power; whilst some have focused on the level at which stigma is played out between individuals, others underline the role of communities and the state in producing and reproducing social inequality.[175;176;186;187] It is not the purpose of the present thesis to explore these theoretical discussions in detail and the interested reader is directed to Parker and Aggleton's useful analysis of HIV-related stigma.[186]

HIV is heavily stigmatised in UK African communities and Africans are less likely than white patients to disclose their HIV status to family and friends; the great fear of many is that their situation might become public knowledge within the local African community and up to 15% do not disclose their status to anyone, including their partner.[137;144;175;181;187;188]

For women, the reluctance is partly accounted for by fear of their partner's reaction. There are reports of women who disclose their status being beaten by their husbands and being forced out of the home.[137;140] Anderson and Doyal's qualitative study exploring the illness biographies and daily lives of 62 HIV positive African women, found that a third of the women had direct experience of HIV-related stigma such as rejection by husband or partners, eviction from their home, special washing or marking of kitchen utensils and refusal to allow contact with children. A further similar proportion expressed anxiety that they would be subject to such discrimination if their status were known.[144]

Fears around disclosure also impact medical care with up to one quarter of HIV infected Africans not disclosing their status to their GP and some patients reportedly feeling extremely uncomfortable about attending HIV clinics for fear of being seen there.[137;140] Not only are stigma and discrimination obstacles for the ongoing treatment of diagnosed HIV infection, but they also impact upon the decision to test, with up to half of Africans tested at specific HIV clinics reporting that a major pre-test concern was the fear of being recognised by someone they know, and this may be even higher amongst those who remain untested.[181]

The HIV-related stigma within African communities is compounded by the discrimination that is directed towards African communities in general, with

some sectors of the media propagating racism and discrimination and serving to increase the general public hostility towards immigrants.[188;189] Recognising this, the Department of Health's framework for action on HIV calls for particular and appropriate support for African communities, which takes account of the extensive difficulties that their cultural and social context brings.[128]

Treatment and Adherence

Although it is widely accepted that the introduction of Highly Active Antiretroviral Therapy (HAART) has had a dramatic impact upon disease progression and survival in countries where the treatment is available (see page 12), there is evidence that the use of antiretrovirals is lower in non-white than white racial groups in some countries.[190] Similar claims have been made in relation to African people living with HIV in the UK.[125;140] However, these claims cite as evidence a small retrospective study of 55 HIV positive Africans seen for care between 1986 and 1993.[131] HAART was not introduced until 1997 and was not therefore the focus of the study, which actually concentrated on chemoprophylaxis for *Pneumocsytis carinii* pneumonia and tuberculosis.

Evidence from the large Swiss HIV Cohort Study suggests that in a Northwest European country with a universal health care system, nationality was not associated with uptake of antiretroviral therapy once the infection had been diagnosed.[53] Project Nasah, a questionnaire based study of 438 HIV positive Africans in the UK, found that access to treatment once HIV is diagnosed is not a particular problem.[137] However, lack of awareness of the availability of medicines to treat HIV might be a barrier to accessing HIV testing in the first place.[191]

A UK based study of 362 patients comparing the virological and immunological responses of African and European participants to HAART concluded that the initial responses were similar in both groups.[192] The poorer longer-term virological response in the African cohort after 9 months, reflected in a higher viral load, was not thought to be related to different patterns in developing drug resistance nor to the presentation with substantially lower pre-treatment CD4

counts, but rather to poorer adherence. Project Nasah showed that a third of respondents had missed one or more treatment doses in the previous fortnight.[137] Although simply forgetting to take medication accounted for some missed doses, the side effects of the medication and the desire to keep the diagnosis from others were important factors.[137]

Adherence to treatment is potentially problematic in a range of chronic conditions, but may be particularly important in HIV where high levels of adherence are needed for successful treatment.[137;193]

Qualitative studies have suggested that there may be particular issues for African patients that might indeed contribute to poorer adherence to treatment regimes.[137;140;144;158] For example, the influence of religious beliefs, which has been discussed on page 44.

Erwin and Peter's focus group study of treatment issues for HIV positive Africans living in London is a frequently cited source for African peoples' views and experiences of living with HIV.[140] The authors found a strongly held belief in the physiological differences between white and black people that appeared to affect their confidence in the appropriateness and effectiveness of the currently available medications. Coupled to this was distrust of pharmaceutical companies and the motives of health care professionals. Fear of discrimination and experimentation appeared to undermine participants' commitment to taking prescribed medication.

Living conditions may make it difficult to adhere to drug regimes. Living in shared accommodation brings difficulties in concealing medicines and where medication requires dietary manipulation, there are particular difficulties for those who have limited access to food or cooking facilities.[160]

However, Anderson and Doyal found that the majority of women in their London based study were highly committed to treatment despite the difficulties they encountered.[144]

2.5.6. Accessing care and use of services

Use of health services and barriers to care

Even in the context of universal health care, migrants and ethnic minorities often face particular difficulties in accessing appropriate health services. The linked problems of unemployment, poor housing and poor health, together with issues arising from discrimination, isolation and uncertain immigration status, all form part of a complex set of barriers that may be particularly pertinent in relation to health care for HIV.[128;132;150;152;154;194]

A UK qualitative study amongst 48 Somali, Ugandan and Nigerian respondents identified a number of difficulties faced by Africans in accessing and taking best advantage of health services (Figure 9).[124]

Figure 9: Difficulties encountered by Africans accessing health services (identified by Elam et al.)[124]

- Lack of awareness of health services
- Limited English language skills and difficulty in making self understood
- Reluctance to ask questions of the GP
- Lack of confidence in GPs who they felt did not ask questions or give them sufficient time
- Among women, a tendency to prioritise other demands ahead of their own health
- Unwillingness to admit health problems in case they jeopardise residency or work status
- Not returning to the GP if the treatment does not work

The general practitioner was widely consulted, and regarded as an important source of advice and treatment. However, experience of GP services was mixed and related to a range of problems including lack of diagnosis, long waiting

times and poor communication. In response, some sought medical advice from alternative sources with greater use being made of emergency services and pharmacies. Some felt able to change their GP whilst others, despite feeling unhappy, reported that they had no alternative but to *'just be quiet and go'*.[127]

Primary care services are well accessed by Africans, with the vast majority having consulted a GP.[165;181] A relatively small survey of Ugandans in London found that utilisation of GP services was high, with 97% of the purposeful sample of 118 Ugandans being registered with a GP.[165] Over 90% had consulted a GP in the previous year with most respondents reportedly happy with the service they had received, although in common with other reports, there were several complaints about poor communication with the GP.[187] A majority (56%) felt that London's mainstream health services were appropriate for Ugandans although 40% felt that there should be closer working with African community organizations. The GP surgery was the most commonly cited place for receiving health information including information about HIV/AIDS, often in the form of a leaflet.

Pathways to HIV testing and the role of general practice

The promotion of HIV testing aims to reduce the proportion of undiagnosed HIV infection thereby facilitating access to effective treatment and care and reducing the risk of onward transmission. It is a key aim of the National Strategy for HIV and Sexual Health and targeting African communities is recognised as an important part of the strategy.[15;136] It is widely accepted that Africans living in the UK present at a more advanced stage of HIV disease than white patients (see page 36). The ways in which some black Africans negotiate their way to HIV-related care are complex. For some, friends and family may be consulted as illness complications unfold and a medical professional consulted only when the illness becomes unbearable.[125]

A large community based survey of HIV testing behaviours among migrant sub-Saharan African communities (the Mayisha Study) found that considerably more needs to be done to facilitate the uptake of HIV testing.[195] The study, the first of

its kind, used 25 trained volunteers from the five target African communities to undertake recruitment and hand out questionnaires. The volunteers were familiar with their local communities and recruited from pre-identified social venues. The authors found that the drivers for uptake of testing were related to individual risk, perceived or actual, rather than being related to the high prevalence in their country of origin or knowledge of high rates of disease amongst migrant populations in the UK. This finding correlates with the claim that Africans are more likely than non-Africans to test because of a preceding event suggesting the possibility of HIV infection, including the development of AIDS or a positive diagnosis in a symptomatic child[13;181;196] It also supports the finding that HIV positive Africans are less likely to suspect their infection than non-African patients.[13;181;196] The lack of perceived risk of HIV infection partly explains the profound shock described by many Africans who test positive, despite being symptomatic at the time of testing.[13;144] Even those who suspect they may have acquired the infection are significantly more likely than non-Africans to delay testing for 12 months or more.[181]

More recently, a nested qualitative study within a second community-based survey of sexual attitudes and lifestyles among black African communities in England (Mayisha II) found that fear of stigmatisation, deportation and perceptions of HIV as a 'death sentence' continue to act as barriers to testing.[159] Among women, principle reasons for testing included fear of HIV infection due to mistrust of their partner or following rape. For both men and women, lack of perceived risk because they were married or had been faithful to the same sexual partner for several years was cited as a reason for not testing.

Delay in testing is multi-factorial and a range of practical, social and emotional issues have been raised as pre-test concerns for black Africans. Table 2 shows the pre-test concerns of HIV-infected African clinic attendees, although the study from which they are drawn was retrospective and results may be affected both by selection and recall bias.[181]

Table 2: Pre-HIV test concerns of black African patients[181]

Statement	**% Very worried (n = 102)**
Effects on your family if you were HIV positive	74
Discrimination if you were HIV positive	68
Fear of dying	66
Not being able to make plans for the future if you were HIV positive	64
Not being able to have children if you were HIV positive	60
Effects on your work if you were HIV positive	55
Partner's reaction if you were HIV positive	49
Bumping into someone you knew at the HIV clinic	48
What the Home Office might do if they found out you were HIV positive	40
That your children might be taken away if you were HIV positive	32
Whether you were entitled to medical care	28
Where to go for an HIV test	20
The attitudes of the clinic staff	13
How to communicate with clinic staff	12

Although primary care services appear to be well accessed by African patients, the majority of HIV infections are diagnosed in hospital or genitourinary medicine settings, not uncommonly with symptomatic disease.[137;165;181;181] There is some evidence to suggest that there might be missed opportunities for earlier diagnosis through primary care.[181] Only a very small proportion of HIV diagnoses in Africans are made in primary care and there is a strong argument for an increased role in facilitating earlier HIV testing and diagnosis.[17;115;137;181]

A study amongst 100 black African women known to be HIV positive found that 62% had symptomatic HIV or AIDS at presentation, and that whilst 71% of these had visited their GP in the 12 months before diagnosis, only 27% recalled a discussion about HIV.[111]

To describe factors associated with HIV testing among black Africans, Burns et al. analysed data from the second British National Survey of Sexual Attitudes and Lifestyles.[196] Natsal 2000 is a stratified probability sample survey of sexual

attitudes and lifestyles among 11,161 British residents aged 16 - 44 years, which includes an ethnic minority boost.[68] Whilst recognising the need to improve the uptake of HIV testing further, the authors suggested that Africans in the UK have a relatively high rate of HIV testing reflecting awareness of risk behaviours and potential exposures to HIV, and that up to a quarter of Africans who undertake HIV testing do so in primary care. However, the results of their analysis should be interpreted with caution because Natsal 2000 data is derived from self report without means of verification.[68] Further, the analysis found no association between rate of HIV testing and antenatal care, as might be expected, given that universal antenatal testing had been adopted prior to the Natsal study period. Additional questions regarding the validity of the results are raised by the finding that 20% of HIV tests in the African participants had reportedly been conducted in family planning clinics. As the authors point out, at the time of the study these clinics were not routinely able to undertake HIV testing and generally referred to other sites.

A number of reports have advocated a role for targeted testing amongst African people and this may be especially urgent as the availability of HAART is making inequality in HIV care even more visible.[17;130;152;181;195] Although targeting a particular group on racial grounds raises concerns regarding perceived racism, it has been argued to the contrary that not offering an HIV test to an African person from fear of how it may be perceived could itself be considered a racially discriminatory denial of appropriate care.[70]

Medical care and community support for Africans living with HIV

There is some evidence to suggest that perceived discrimination and distrust of the medical profession may be a barrier to accessing health services for some African patients living with HIV.[140] In focus groups conducted with HIV infected African patients in London, some participants believed that they received inferior treatment and even that some treatment was chosen deliberately to be detrimental to their health. Whilst similar mistrust of the health care system and providers has been found amongst many African American patients, Erwin and

Peters point out that some of the negative perceptions found in their study may be explained by cultural and communication difficulties.[140;197] For example, they found that African patients and their relatives find the concept of intravenous feeding and denial of oral feeding particularly difficult.[140]

In contrast, other qualitative studies and surveys have found HIV services to be highly rated by African patients and clinic staff are generally trusted for the advice they give.[137;144;158] The findings of a questionnaire study of 214 HIV positive Africans in London suggested that health care professionals are the most trusted source of credible information on how to live with HIV.[158]

The importance attached to maintaining confidentiality appears to affect the level of engagement with medical services with some avoiding the use of HIV related services altogether.[198] Some Africans choose not to attend a clinic which is close to home for fear of being identified by members of their own community, instead taking long bus and train journeys to reach their chosen clinic.[140;144] Childcare is particularly problematic for women who do not disclose their status to family or friends, making it difficult to call on their support in order to attend hospital or other appointments. Such restrictions may make it difficult for them to see the same doctor at each appointment, adversely affecting continuity of care. For some, childcare issues mean they keep their clinic visits as short as possible and don't spend time on accessing other information that may be available to them.[140]

Late presentation (see page 36) inevitably means more severe illness; Africans are disproportionately represented amongst patients who access treatment as an in-patient and a greater proportion require medical treatment for symptomatic and more advanced disease soon after diagnosis.[13;140] Thus many are faced with psychosocial and disease management issues at the same time.[198]

The medical treatment and other service needs of HIV-infected heterosexual African men may present a particular challenge to service providers. There is some evidence to suggest that African men feel uncomfortable accessing services that were designed for men who have sex with men and despite some new

initiatives by London based African organisations it remains difficult to encourage African men to engage with support groups and services.[198]

Many African people in the UK suffer social exclusion and feel isolated. In the African setting the extended family is a source of support that may not be available in the UK.[132] In response, a number of African community organisations provide information and help, access to health and social services and provide advocacy and translation services but many of these are London based.[125] However, some have claimed that there are too many organisations that duplicate services by representing different nationalities or tribes and as a result struggle to obtain sustainable funding.[24;140] In addition, there have been reports of political in-fighting between groups which appear to represent different parts of the Ugandan community in particular. Possibly, this reflects some of the political and ethnic conflict that brought Africans to London in the first place.[198]

The use of such voluntary support groups appears to be variable. For some, they provide a range of social, emotional and practical support, whilst for a significant number their use is limited by fear of information being passed on to others in the community.[144] Outside London the picture is not well documented, but it is likely that the provision of community support services for Africans is less comprehensive.[24;128]

HIV prevention services

UK African communities are not homogeneous (see page 32), rather they are socially, culturally, linguistically and numerically diverse and as a result may have distinct and different needs in terms of HIV prevention work. To be successful, HIV prevention work with African communities must be culturally sensitive and engage people based on their belief and communication systems.[125;140;165] This includes addressing key cultural issues which appear to put African people at increased risk of transmission of HIV including perceptions of condoms and culturally defined sexual practices.

The consistent use of condoms continues to be advocated as an essential and effective method of preventing HIV transmission, reducing the per-contact probability of HIV transmission by as much as 95%.[199;200] However amongst some African groups traditional beliefs and prejudice against condoms limits their use (see page 39). Although condoms are widely distributed by many agencies it is clear that the use of condoms within African communities involves much more than making them available.[158] The desire for children, the lack of adequate negotiation skills and negative attitudes to condoms themselves have all been identified as barriers, and to capitalise on the benefits of condom use in HIV prevention requires a greater focus on interventions that change attitudes to their use.[125;158]

For younger members of African communities there is evidence to suggest that peers may be an important source of information and amongst the most credible sources of HIV related information for both primary and secondary prevention.[158]

2.6. Summary of the review and questions that remain to be answered

This chapter has outlined key aspects of the HIV epidemic and in particular has discussed the disproportionate burden of disease amongst black African communities in the UK. It has highlighted that Africans tend to present later in the course of disease than non-Africans, with more than a third estimated to be living with undiagnosed infection.

It is widely accepted that the availability of HAART since 1996 has resulted in dramatic decreases in the risk of AIDS and death. However, the effectiveness of HAART is influenced by the CD4 count at start of treatment. Whilst debate continues regarding the optimal starting point when the CD4 count is above 200 x 10^6/l, there is widespread agreement that below this level antiretroviral treatment is indicated.[6;51;53;55]

Increasing HIV infection within UK African communities, combined with later presentation and therefore more limited uptake of antiretroviral treatment at the optimum time, has negative consequences both for the health of individual African people and for wider public health. There is therefore a need, recognised by the National Strategy for Sexual Health and HIV, to reduce undiagnosed and late diagnosed HIV infection in UK African communities.[15]

However, as this chapter has shown, little is known about the testing decisions and testing experiences of this group. Some studies have sought to elucidate factors associated with the decision to take an HIV test but have only succeeded in identifying sociodemographic factors which are statistically associated with testing, and have failed to give insight into the decision making process itself.[69] Studies which have asked respondents to identify their reasons for having or not having a test have largely been limited to gay and bisexual men. The current study will address this gap by exploring the perceptions and experiences of African people in relation to HIV testing.

In order to develop culturally appropriate services for black African communities it is necessary to gain a better understanding of the attitudes, beliefs, gender disparities and cultural practices as they relate to HIV in general and HIV testing in particular.[125] By exploring the worldviews of African people through in-depth interviews, this study seeks to gain deeper understanding of these issues and how they impact upon decisions about HIV testing.

Little is known about the barriers that exist in relation to the use of sexual health services and there is a lack of evidence on the perceived accessibility or appropriateness of these services. Indeed, access to care by black Africans has been identified as an issue requiring further research, which may help our understanding of the barriers to HIV testing.[181] Most provision of HIV testing has been confined to genitourinary medicine clinics and this may itself be a barrier to uptake of testing. There is limited research evidence to show how clients access these clinics and where they are accessed it is unclear how awareness is raised, whether through peers, other health professionals or through other 'gate-

keepers' such as help-lines or community groups.[69] This study will explore these issues from the perspectives of professionals working within the care system, both statutory and non-statutory sectors, and from the perspectives of African people. This will enable a valuable comparison of the perspectives of service providers and service users to highlight where there may be a mismatch.

This review of the literature has highlighted that black Africans in the UK face HIV diagnosis in a different context from that experienced by their white counterparts. Immigration status and practical issues relating to housing and employment may be compounded by uncertainties over entitlement to treatment. For Africans who are known to be HIV positive there may be ongoing fears relating to confidentiality, made particularly important by the stigma attached to HIV in African communities. The limited number of studies which have identified some of the issues faced by HIV positive African patients cannot inform us about Africans who do not access services; those who may be living with undiagnosed infection and have chosen not to be tested. Amongst this latter group, concerns are likely to be greater and may be more expansive. The current study specifically seeks to explore the needs and experiences of African people who have undergone HIV testing and those who remain untested. Thus it will enable a comparison to be made between these two groups, adding to our understanding of the issues which may be particular barriers to HIV testing.

Some studies point to the unmet need for basic information regarding HIV testing, treatment and intervention.[128] There may well be a need to improve awareness of the benefits of early testing, especially the benefit of testing in asymptomatic patients but further research is needed in order to explore the most appropriate interventions to achieve this objective. Again the current study will investigate these issues and will explore culturally appropriate ways to improve the uptake of voluntary HIV testing.

This review has shown that primary care is frequently accessed by African people and may present an opportunity for HIV prevention work and an appropriate route to HIV testing. However, there is some evidence to suggest

there may be important gaps in knowledge and confidence amongst primary care health professionals. Further research is needed to elucidate these potential barriers to HIV testing in primary care and to better understand the perceptions of GPs held by African people.[109;181] This study begins to address this gap in currently available research by uncovering African peoples' perceptions of their health carers, with a particular focus on their past and potential future use of primary care services.

Further research is needed to explore the perceptions of discrimination that have been highlighted in some studies. Distrust of the medical profession and fears around antiretroviral therapies that may have arisen from differences in cultural beliefs and experiences of health care in the UK require further work in order that, where appropriate, staff cultural awareness training can be introduced.[166] This study seeks to explore the relationship between professionals and Africans from the perspectives of each group of participants. Perceived cultural barriers and difficulties encountered by professionals will be specifically investigated. Issues of perceived racism will be addressed in both sets of interviews.

In summary, the review of the literature has identified a number of issues that need further investigation. In addressing its stated aim of exploring how to improve the uptake of HIV testing in UK African communities, this study seeks to meet these research needs. To achieve this the study explores the experiences, knowledge and attitudes of professionals and African people to HIV testing, elucidates perceived barriers to testing for Africans in the UK and considers culturally appropriate ways of overcoming them.

The next chapter will outline the methodology and methods that underpin the study.

CHAPTER 3. METHODOLOGY, DESIGN AND IMPLEMENTATION

3.1. Introduction

The aim of this chapter is to discuss the methodological approach and empirical methods used in this study of the barriers to timely HIV testing in UK African communities.

The review of the literature has highlighted the importance of early testing for HIV, especially in a setting like the UK where treatment is available. It is also apparent from the literature that information is lacking in the British context regarding the HIV testing needs and experiences of African people. This study attempts to address this issue, taking an exploratory approach to uncovering the key issues and challenges involved in increasing the uptake of HIV testing.

Most of the work that has been conducted in the British context on HIV and ethnicity has been quantitative in nature and more influenced by biomedical perspectives than social perspectives on health.[28] This approach can lead to a 'black box epidemiology in which ethnicity substitutes as a *cause* of observable health variations rather than a common denominator requiring further explanation'.[28] Whilst these quantitative studies of HIV in Africans living in the UK go some way to enumerating the size of the problem, what is now required is to explain and to explore this phenomenon by unearthing data that are not easily accessed by quantitative means; '*not so much how many, as how and why*'.[201]

It is widely acknowledged that qualitative studies have an important contribution to make to health services research, and particularly so in the field of sexually transmitted infections and HIV where many of the social phenomena being studied are intensely personal and private.[201] In the study of marginalized, vulnerable and disadvantaged groups, especially where the subject of research

may itself lead to stigma, qualitative research may have special importance in 'addressing the questions of *humanity* which are intimately linked with issues about *equity* and may ultimately be shown to be important in promoting *effectiveness*'.[202] (original italics)

The rest of this chapter will discuss some philosophical perspectives underpinning qualitative research methodology, focusing particularly on those that inform the current study. It will then present a detailed account of the empirical methods used for the fieldwork and analysis.

3.2. Qualitative research

Qualitative research methods were developed within disciplines such as anthropology and sociology in an attempt to explore and understand the social world in 'natural' rather than experimental settings. Contemporary qualitative research is not a single entity, but is rather a broad umbrella term, encompassing enormous diversity. It is a complex, changing and often contested paradigm comprising multiple methodologies and research practices, and providing a precise definition of qualitative research is therefore not an easy task.[203]

Denzin and Lincoln describe qualitative research as:

> *... a situated activity that locates the observer in the world. It consists of a set of interpretive, material practices that make the world visible. These practices transform the world. They turn the world into a series of representations including fieldnotes, interviews, conversations, photographs, recordings and memos to the self. At this level, qualitative research involves an interpretive, naturalistic approach to the world. This means that qualitative researchers study things in their natural settings, attempting to make sense of, or to interpret, phenomena in terms of the meanings people bring to them.*[204]

There is fairly wide consensus that qualitative research is a naturalistic, interpretive approach, concerned with the meanings that people attach to various phenomena such as actions, beliefs, decisions and values within their social

world, with one of the central motifs of qualitative research being the way in which the people being studied 'understand and interpret their social reality'.[205]

However, there is considerable variation between and within disciplines about what constitutes this type of research activity, with a confusing range of ontological and epistemological positions often cited in their defence. This extensive theorising around ontology (the nature of the social world and what can be known about it) and epistemology (how it is possible to know about the world) can sometimes be circumvented or even lost in the fact that many 'recipe' books of techniques for conducting and analysing qualitative research are now available. This is especially so within health services research, where the focus is often pragmatic and researchers may not have a social science background.[206] These 'technical' accounts tend to emphasise the standardisation of methods and ensuring rigour.

Some qualitative researchers, such as Miles and Huberman, approve of the increasing number of researchers who are pragmatically orientated and ecumenical in their view of the world, claiming it is possible to develop practical standards that can be applied across different perspectives and which can be used to judge conclusions.[207] However, others are critical of a purely pragmatic orientation, arguing that research procedures cannot be isolated from commitments to particular versions of the world and calling for qualitative researchers to go beyond a 'cookbook' approach to research methods and to engage, at least to some degree, with the underpinning theoretical principles.[206;208;209] Thus, health researchers are increasingly requested to provide evidence of reflection upon the philosophical positions that have influenced their research process.[210]

Within the qualitative paradigm there are several different schools espousing often contradictory ontological and epistemological positions. These include: interpretivist perspectives, encompassing phenomenology, ethnomethodology and symbolic interactionism; critical theory, including feminist perspectives and

neo-Marxism; post-structuralism; and post-modernism.[211] There are complex debates between and within disciplines regarding these different viewpoints.[212]

It is not the intention here to enter this debate but rather to focus on the aspects of these different approaches that have informed the choice of methods used in this study.

Some authors have claimed that different qualitative traditions, being based on varied ontological, epistemological and methodological assumptions, represent unique worldviews that necessarily have practical implications, which mean it is not possible to move between them.[213] Others call for a way to build links between different traditions,[214;215] blending insights from various schools,[207] asserting that this aids the handling of complex qualitative data,[216] even though such an approach may present a 'bewildering array of conflicting considerations'.[217]

Rather than allowing philosophical positions to override pragmatic considerations, the approach taken in this study is to attempt a balance between philosophy and pragmatism.[205] As Hammersley points out, there is no escape from philosophical assumptions for researchers, even if philosophy is not seen as fundamental to the activity of research.[218] For this study it was clear from an early stage of development that the perspectives of a number of schools could and should influence the research undertaken. The eclecticism of borrowing from a number of different traditions can be a significant strength but only if the beliefs underlying the practices are acknowledged and discussed.[203] It is hoped that by acknowledging the philosophical underpinnings of the research and by reflecting upon her own beliefs and their relationship to her research practice, the author will evade criticisms of 'generic qualitative research' which fails to do so, and thereby inhibits evaluation of its quality.[203]

The remainder of this chapter will attempt to address this issue by considering the perspectives that inform the position adopted in this study and the methods used for the empirical work.

3.2.1. Ontological stance - Subtle realism

Ontological questions concerning whether there is a captive social reality and how it should be constructed stand at the heart of the debate between the different philosophical underpinnings of research. At one extreme end of the spectrum 'relativist' ontologies claim that conflicting realities can co-exist because realities are but mental constructions which are socially and experientially based.[213] In this 'antirealist' stance it is claimed that knowledge and truth are the result of perspective, and are created by the minds of actors. Individuals do not *discover* knowledge; rather they create or construct it.[217] In the research process researcher and respondent create a particular social world, rather than representing some independent reality, and this world is no more or less true than any other.[218] This position is at the opposite ontological extreme to 'realism' which asserts the existence of an external reality that is independent of people's beliefs or understanding about it.[203]

Hammersley has responded by outlining a 'subtle realist' perspective which refutes the need to take the extreme positions of either relativism or naïve realism.[218] This subtle realist approach has influenced the philosophical position of the current research. That is, the author accepts that the social world does exist independently of individual subjective understanding, but that we can only access that reality through the interpretations of respondents and that these are further interpreted by the researcher.[203] The current study is also informed by the position that whilst knowledge is based on assumptions and is a social construction, there are enough stable properties within social phenomena to make them knowable.[207]

In the context of a research study the interpretations of respondents are influenced by their own vantage points and as these differ, so they yield different types of understanding. Further, to understand the meanings of the actor's life world they must be interpreted. The researcher interprets the meanings given by the respondent, offering a 'construction of the constructions of the actors in the

study',[217] and is concerned with presenting a 'multi-voice reconstruction' of the researcher's own interpretation.[217]

The existence of an external reality is not called into question by these diverse interpretations. It is itself diverse and multifaceted, the different perspectives adding richness to our understanding of the various ways in which that reality has been experienced. Since the aim of research is to convey as full a picture as possible of the multifaceted reality, the diversity of perspective is embraced as a strength.

3.2.2. Epistemological stance - Interpretivism

The assertion that the social world can be studied in terms of invariant laws just like the natural world formed the basis of the paradigm known as positivism; a major influence upon social research throughout the twentieth century.[203] The positivist ontological construction of the world is one of empirical observation and its epistemological perspective is that things only exist if they are observable and measurable.[219] In more recent decades the dominance of positivism as an epistemological stance has been challenged, particularly from within the discipline of sociology, with theorists beginning to re-think the ontological and epistemological premises on which social research is based. Hammersley and Atkinson claim that the term 'positivism' has now become little more than a term of abuse among social scientists,[220] although others prefer to identify themselves as 'post-positivists', remaining within the same essential set of beliefs but having responded in a limited way to the most problematic criticisms of positivism.[213]

Those practising qualitative research have tended to place emphasis on the value of human, interpretative aspects of knowing about the social world, and the importance of the investigator's own understanding and interpretations of the phenomenon being studied. The interpretivist approach is attributed to Husserl (1859-1938) whose work was further developed during the 1960s and 1970s by sociologists who were dissatisfied with positivist and quantitative approaches to examining human behaviour, asserting that these techniques were divorced from

everyday life. Interpretivism, instead, seeks to understand 'the complex world of lived experience from the point of view of those who live in it'.[217] It does this by exploring how people interpret, assess and make sense of their experiences and the world around them by attaching meanings (norms, values and beliefs) to objects and events.[217]

By gaining knowledge of how people assess the world, interpretivism aims to account for how people choose courses of action. Social action and human behaviour cannot be explained by simple cause and effect relationships but rather are evolving, purposeful and intentional responses based on actors' interpretations and application of meaning to events. Meanings are established, attributed and negotiated through social interaction and interplay with the social and cultural environment as new experiences are encountered.[208] As it is these meanings that can make sense of behaviour, interpretivists claim that the meanings people attach to their actions, and the ways in which people act out their everyday lives, must be investigated. Context, they assert, is very important when seeking to understand specific behaviours, such as an individual's response to illness. According to the interpretivist position, individuals interpret stimuli in ways that are continually revised as new experiences are encountered, which shapes their actions. Thus, the same stimuli can mean different things to different individuals and also to the same individual at different points in time.[218]

Meanings are therefore changeable, context bound and multiple, varying with situations and social interactions which themselves are in constant flux. In recognising this, interpretivism calls for a flexible approach that respects such complexity, avoiding a static approach that attempts to uncover fixed rules. Adopting an interpretivist perspective therefore requires a particular approach to research and the generation of knowledge. An in-depth approach is required in order to access actors' meanings and motives, which enables the researcher to delve at the level of the individual's subjectivity. Knowledge should be acquired by *verstehen* - that is, empathetic understanding through taking the perspective

of the person or situation being researched in order to understand the meanings they attach to their behaviours and experiences.[215;218] Knowledge acquired by *verstehen* accesses motive and can therefore be explanatory, but it requires immersion so as to 'feel one's way inside the experience of the actor' and to 'catch the process of interpretation' through which action is constructed.[221]

Phenomenology

To some extent the current study draws on the sub school of interpretivist thought known as phenomenology, although does not adopt its full range of ideas and methods, particularly in relation to analytical approach and the injunction for the researcher to 'bracket' her own assumptions.

Phenomenology owes much to the work of Alfred Schutz who bridged sociology with Husserl's more philosophical phenomenology[222] and was interested in the ways ordinary members of society attend to their daily lives, arguing that the focus should be on ways that individuals experience their life world – the world that every individual takes for granted – especially how individuals consciously develop meaning out of social interactions.[223] According to Schutz, each individual approaches the life world with a stock of knowledge, made up of commonsense constructs and categories that are social in origin. It is with these stocks of knowledge – images, theories, ideas, values and attitudes - that an individual interprets experiences and makes them meaningful.[222] The social world is not homogeneous and perceptions of the social world are complex, some being shared and some being unique to individuals.[224]

Central to this school of thought is the concept of 'type'. Schutz claimed that the meanings that people hold in common are taken to be typifications or ideal types of the phenomena. At each moment in life, stocks of knowledge are available from past experiences, and are articulated in a 'typified' manner.[225] The individual anticipates and responds in terms of these generalised typical expectations, until something new is discovered that contradicts these expectations. These stocks of knowledge are therefore the means available for

action. They are constantly being reconfirmed or modified in the light of new experience as participation in life continues.

This position therefore holds that knowledge is a historically and socially derived phenomenon and meaning is 'a certain way of directing one's gaze at an item of one's own experience'.[224] Schutz postulated that experience could not be grasped as it occurs but only reflectively, once it had passed and, further, that behaviour has meaning because it is an experience that has occurred *and* has been looked at reflectively. As Donovan points out 'it is the act of the reflective glance that singles out elapsed experiences and endows them with meaning'.[226]

This strand of phenomenological thinking has important implications for this study, because it means that one cannot interpret the experiences of another directly, but only through picturing their reasons and motives. The interpretation of reasons and motives is based upon previous experience, cultural inheritance and, importantly, the context. The researcher aims to understand the deeper levels of understanding, and this may involve putting herself into the place of the other and imagining 'selecting the same motives to thus understand why the particular actions were chosen'.[226] The meaning and knowledge attached to HIV by the African participants in the current study is influenced by their experience of HIV and AIDS within the context of lived experience in Africa. Further, their reasons and motives, according to the phenomenological stance, are further interpreted in the light of the experience of the particular cultural and social settings in which many African people live within the UK. It is only in empathetically seeking to engage in the lived experience of participants, particularly in relation to experience of HIV and AIDS in a setting where medical care, for the most part, has been unavailable, that the researcher can gain access into the stock of knowledge and therefore the meanings held by research participants. As Cresswell points out, the phenomenological perspective is based on the premise that:

> *... human experience makes sense to those who live it, prior to all interpretations and theorizing. Objective understanding is mediated by subjective experience, and that human experience is an inherent structural property of the experience itself, not constructed by an outside observer.*[223]

The researcher's own experience of living in Africa undoubtedly influenced her ability to gain insight into the stock of knowledge held by some of the research participants. She had lived in a remote and rural part of East Africa for over two years, for some of that time as the only European within a fifty mile radius, and had much first hand experience of living within an African community; its customs, language and culture, becoming assimilated into the community and accepted by it.

The researcher's professional experience as a medical practitioner, both as a GP and prior to that as a hospital doctor, also enabled some access to the stocks of knowledge of both professional and African participants. Working as a GP, the researcher has first hand knowledge of medical processes involved in HIV testing and the arrangements for care within primary and secondary care. She has experience of working in a practice where a number of immigrants were registered and, additionally, has worked as a primary care physician in the setting up and delivery of services for refugee and asylum seekers, many of whom are from sub-Saharan Africa. In all of these contexts she has encountered and engaged with some of the particular issues that arise for African people who are living in the UK; issues relating to work, family, finance and culture, as well as those relating to health.

Within the framework of phenomenology, language plays a leading role. Words and phrases, viewed as a process of typification, are the constitutive building blocks of the social world and through the use of ordinary language, typification creates the sense that the life world is 'familiarly organized and substantial, simultaneously giving it shape and meaning'.[224] The shared meaning that is expressed in common language is a reflection of 'intersubjectivity' - the assertion that individual actors experience the world and their interactions with others in

fundamentally the same way - and the belief that most phenomena, such as events and facts will be *interpreted* in the same way to an extent sufficient for practical purposes.[227;228] As Holstein and Gubrium describe:

> *Intersubjectivity is thus a social accomplishment, a set of understandings sustained in and through the shared assumptions of interaction and recurrently sustained in processes of typification.*[225]

Again, the researcher's experience of living in Africa was significant in this regard. Although the African participants were from a range of countries in Africa, there were aspects of linguistic expression which resonated with the researcher's previous experience and understanding. Not only was the researcher more easily able to understand participants' accents, she was also aware of meanings bound up within particular words and forms of expression. One example of this relates to an understanding of descriptions of religious belief and the distinction sometimes made by participants between being 'Christian' and the concept of being 'Saved'. The former often involved regular church attendance and general assent to a set of beliefs, whilst the latter additionally emphasized distinctive modes of behaviour and often called for a greater commitment. Understanding these semantic differences helped to inform the researcher's interpretation of the interview conversations.

Symbolic interactionism

Social interaction as the conveyor and constructor of meaning and the concept of intersubjectivity are also inherent to symbolic interactionism. With its roots in interpretivism, this school of thought holds that social interaction - social action that is characterised by an immediately reciprocal orientation - has a symbolic character through which individuals actively construct reality in everyday life. The empirical starting point for research within the tradition of symbolic interactionism is the subjective meaning individuals attribute to their activities and their environments.[229] Herbert Blumer formulated the 'three simple premises' of symbolic interactionism:

> *'The first premise is that human beings act toward things on the basis of the meanings that the things have for them ... The second premise is that the meaning of such things is derived from, or arises out of, the social interaction that one has with one's fellows. The third premise is that these meanings are handled in, and modified through, an interpretative process used by the person in dealing with the things he (sic) encounters'.*[221]

The different ways in which individuals invest objects, events and experiences with meaning thus form the central starting point for research, with the reconstruction of such subjective viewpoints being the instrument for examining social worlds. A central concept therefore is Blumer's injunction that 'one has to get inside the defining process of the actor in order to understand his action'.[221]

Within this theoretical framework, 'symbols', which may take the form of language, signs, gestures or anything else from which meaning can be constructed,[230] form the basis of the social world. Individuals and societies develop through people's interaction with symbols and as individuals learn to use these symbols, so they develop a sense of themselves. They also develop a sense of themselves as they learn to see themselves the way they believe others see them.

As with phenomenology, language is a central focus of symbolic interactionism and is an important factor in shared meaning. Shared meaning is developed in the course of interaction which is itself seen as people seeking to achieve practical results in cooperation with each other. Social interaction produces meanings and it is meanings that make up our world. Thus, there is a sense in which we create our world by giving meaning to it.[231] George Herbert Mead was amongst the first to employ symbolic interactionism as an approach to qualitative research. His view of the social world, and the heart of symbolic interactionism, is concerned with the inner experiences of the individual and how the self emerges from the social process, developing in childhood through the interaction with significant others.[221] Mead argued that a human being has a self and, therefore, a person can be the object of his or her own actions.

In external conversations we can see how social interactions produce meanings, which go on to make up our world. This sense of creating our world by giving meaning to it also occurs internally between different parts of the self, the 'me', the way that others see each individual actor and the 'I', the part that looks at the self. The conception of self describes the process of socialisation, as all the external conversations pass through the internal channel. It is through this process that the individual can take on a social conscience and can view herself as the society as a whole views her.[231]

This process will influence the social interaction that takes place during a conversation, in what Cornwell described as 'public' and 'private' accounts.[232] The actor seeks to say what is acceptable to others through public accounts. Private accounts, however, are those which are understood and accepted within certain social networks and are not often divulged to 'strangers'. It is these accounts, which 'spring directly from personal experience and from the thoughts and feelings accompanying it'[232] that this study particularly seeks to access, whilst recognising that there is always likely to be some 'gap' between the essentially 'public' account given in the interview setting and the intensely personal and 'private' account of experiences.

The construction of self as a combination of the 'I' and the 'me', according to symbolic interactionism, enables not only socialisation but also leads to a process of role-playing in which we play society's 'games' and become adequately functioning members of society. This perspective on the individual's ability to 'function' and, indeed, to access society's benefits including healthcare and social support has informed the current research. The researcher has explored cross cultural considerations in this study, being aware that meanings attached to symbols may not be shared with the indigenous populations, and that the rules of the 'games' may not be known by a migrant community with, possibly, vastly different experience and understanding.

An important feature of symbolic interactionism, with particular relevance to the current study, is that it is grounded in the empirical world of the participants. Thus if the person's experience of HIV and testing is to be understood, then symbolic interactionism, with its emphasis on gaining perspectives by 'learning the language of the participants, with all its nuances, gestures, actions and appearances', may be a particularly useful framework for allowing the researcher to get closer to the phenomenon under study, amongst a culturally distinctive group of immigrants.[230] In the current research it has been especially important to pay attention to the symbolism of HIV, recognising that it has associations which extend far beyond a medical diagnosis, variously representing 'death', 'promiscuity', and 'curse' for example.

3.2.3. Methodological issues

The theoretical positions that underpin the present qualitative research demand that appropriate methods be adopted for the empirical work. A bridge between the theoretical and the empirical is provided by grounded theory,[233;234] which has been described as a 'style' of approaching qualitative research, rather than a specific method or technique.[235]

Grounded theory

Grounded theory methodology emerged from the tradition of symbolic interactionism as a way of developing emergent theories of social action from the data.[203] It was defined by its originators, Glaser and Strauss, as 'the discovery of theory from data systematically obtained from social research'.[236] The methodological approach, formalised by Glaser and Strauss in 1967 and further developed by Strauss and Corbin,[237] provides guidelines and strategies for qualitative data collection and analysis. It entails a cyclical process of induction, deduction and verification, together with a set of strategies for analysis to improve the reliability and theoretical depth of the analysis.[234] Researchers progress from a position of general enquiry at the beginning of a research project

to the discovery of social processes, and the generation of theory and concepts that seek to explain the phenomenon under study.

The central principle espoused by grounded theory is that theory should be generated inductively through systematic and detailed data collection. Interpretations are discovered and 'borne out of the materials'.[236] However, a number of variations in grounded theory have emerged with its development. These can broadly be classified into objectivist and constructivist approaches, the latter giving more attention to the way both data and analysis are created from the shared experiences of researcher and participants and the researcher's relationships with the participants.[233;238]

As originally conceived by Glaser and Strauss, and in response to what they described as the imbalance created by an over-emphasis on the verification of theory in sociological research, a grounded theory approach seeks to generate theory in the absence of an *a priori* conceptual framework or hypothesis. More recent developments within grounded theory allow for the researcher to bring 'sensitising concepts'[217] to the research.[233;239] Strauss and Corbin claim that there is unquestionable advantage to researchers being theoretically sensitised by their reading, training, and experience, and by the explicit theories they might initially bring to the research, arguing that this is a realistic and balanced modification of the original presentation of grounded theory.[240] In the present study, concepts of risk and stigma are examples of sensitising concepts that were carried into the study and refined as the research progressed.

Inevitably, a great deal of relatively unstructured, rich and complex data is generated through the qualitative enquiry. The methodological approach of grounded theory aims to provide the researcher with a way of systematically interpreting, unravelling and organising this data by providing a set of strategies which include generation of low-level categories, constant comparison, theoretical sampling and the search for deviant cases.

A common feature is the requirement that research is a *process* in which data collection and analysis 'should blur and intertwine continually, from the beginning of investigation to the end'.[236] Theory is built from the data, there is no single stage of analysis but rather it is an iterative and cyclical process:

> *Analysis begins with the first interview and observation, which leads to the next interview or observation, which leads to more analysis, more interviews or fieldwork...Therefore there is a constant interplay between researcher and the research act.*[241]

A key feature of grounded theory that has shaped the analytical approach of the current study is 'constant comparative analysis', the process of repeatedly and methodically comparing data codes for variety in meaning, allowing the generation of more abstract theoretical categories.[236] These categories then form the building blocks of theory development. Hence the theory is described as 'grounded' because it will be generated from the data.

'Theoretical sampling'[236] is a further central tenet of grounded theory, and was adopted in the conduct of the current study. Data collection and analysis are not sequential but rather rely upon an iterative process in which the data obtained shape further data collection and analysis so that theory is 'discovered, developed and provisionally verified through systematic data collection and analysis of data pertaining to that phenomenon'.[241] Sampling continues until theoretical saturation is achieved, the point at which new data show no new theoretical elements but rather are confirming what has already been found.[236] Important to this process is the search for and selection of 'deviant or 'negative' cases (exceptions to emerging patterns) that can illuminate areas of difference and contradiction and provide disconfirming evidence providing greater depth and strength to the theory.[234]

3.2.4. Summary

The methodology underpinning the empirical research in this study drew on many of the principles of the different approaches described above. It was informed by phenomenology, as the meanings individuals attached to their behaviour were explored. Some aspects of symbolic interactionism were relevant, in relation to self perception and the values and beliefs associated with HIV and AIDS. Principles and techniques of grounded theory approaches were central to the data collection and analysis process, although elements of the methodology were used rather than adopting the entire range of formal procedures.

The methods and techniques used in this study will now be outlined.

3.3. Empirical design and methods

The main purpose of the study was to explore ways of improving the uptake of HIV testing in UK African communities. Because the process of HIV testing involves both professionals and African patients, a study design was chosen that would enable the exploration of barriers to testing, and how they might be overcome, from the perspectives of both groups.

Qualitative research involves using a variety of empirical materials that will increase the understanding of a particular phenomenon.[212]

> *The ethnographer learns about culture in basically three ways: (a) observation – what people actually do, as well as examination of artefacts of any sort, (b) discussion – what people say they think, believe or do, and why, and (c) reflection – what the ethnographer infers or interprets. (Helman 1991 quoted by Gilchrist[242])*

The current study moved through a number of stages as the various materials were explored. It was understood from the outset that the researcher needed to become 'sensitised' to the subject of the research inquiry.[241] Thus, the first phase of the empirical fieldwork involved a process of naturalistic inquiry using unstructured non-participant observation and conversation, and participant

observation, in which the researcher becomes a part of the setting or process being studied. As Fetterman points out, the most important aspect of fieldwork is 'being there', to observe, to ask insightful questions and to write down what is seen and heard.[243] In this study the researcher was able to learn more from attending clinics, meetings and events than might have been possible by using only more structured qualitative methods such as interviews. It necessarily requires documentation in detailed fieldnotes, a practice that the researcher adopted throughout the research process.[244]

The second and third phases of the fieldwork used qualitative interviews with professionals and lay African people respectively to gain a deeper understanding of how interpretations, perceptions and meanings are constructed, attached and shared. Uncovering the worldviews of both professionals and African people, the interviews set out to explore how their perspectives are negotiated and influenced through social interaction, shaped by past experience and modified by wider social and political influences.

Although to some extent chronologically and methodologically distinct, the intention being for each phase to inform the next, there was inevitably some overlap between these stages of research.

3.3.1. The sensitising phase

The first stage in the process of sensitisation involved the researcher spending time in both a sexual health clinic and within the HIV medical service in an acute NHS Trust in Bristol. During this time she observed processes, people and conversations, asked questions and noted what was seen and heard. These observational methods, which have been referred to as 'naturalistic' because they take place in natural rather than in experimental settings, can be particularly illuminating because the researcher sees and hears for herself, rather than relying on accounts given by others.[245] Subsequently this led to participant observation of the HIV testing process and the management of HIV infected individuals. The researcher was given access to the pre- and post-test discussion process and to

HIV outpatient clinics and case discussion. The researcher's status as a medical doctor is likely to have facilitated access to these sites. Clinicians explained, before the patient entered the room, that there was 'another doctor' present, that this doctor was conducting research, and asked for permission for the researcher doctor to be present during the consultation. In all cases permission was granted and the researcher was able to participate in the consultation. Other opportunities to become sensitised to the research subject were sought and taken up. These included participant observation of a voluntary support group for HIV positive African women and participation in community awareness events that have taken place as part of World AIDS Day and Refugee Week.

Immersion in the setting enables the researcher to hear, see and begin to experience reality as the participants do, learning directly from her own experience.[246] Further, the process of sensitisation enabled the researcher to identify a number of issues to be covered in the research including, for example, issues around the structure of services and how they are resourced, including the lack of appointment availability. Participation in a number of HIV-related events had the additional benefit of enabling contact with, and greater acceptance by, professionals working in the field, and fostered good relationships with the key players in the geographical setting of the research.

The rest of this chapter will outline the sampling, recruitment and methods of data collection, first for key informants and then for African participants. The majority of the interviews, and the greatest methodological and practical challenges, were with African participants. Thus, whilst the empirical methods relating to the key informant interviews will be outlined first, greater emphasis will be given to the African participant interviews. This will be followed by a description of data analysis and interpretation processes.

3.3.2. Key informants

Partly informed by the observational methods mentioned above, a series of 'key informant'[242] interviews were conducted with professionals from a range of

statutory and voluntary organisations with particular responsibility, interest or expertise in HIV. In anthropological or ethnographic research such 'key actors' have been traditionally used primarily as sources of information, helping the researcher gain insight into the contextual background of the research setting or problem.[243;247] One of the cited advantages of using the key informant technique is the quality of the data that can be obtained in a relatively short period of time.[248]

Interviewing key informants

Key informants have been described as 'individuals who possess special knowledge, status, or communication skills, who are willing to share their knowledge and skills with the researcher and who have access to perspectives or observations denied the researcher'.[249] They can be 'important sounding boards'[243] and in the current study, key informant interviews served both as further sensitising devices to continue the conceptual development of the research, and to map out the key issues in relation to the debate surrounding testing for HIV in African people. Being 'individuals who are able to teach the researcher',[242] they provided important background factual knowledge, including information regarding the scope of the perceived problem and the current level of service provision.

The data arising from these interviews informed the next stage of the research, the in-depth interviews with individual African interviewees. In some cases key informants acted as 'gatekeepers'[220] and were willing to provide introductions to African people with whom they were involved professionally. Not only can key informants 'provide the researcher with both access and sponsorship',[242] but they may have particular importance in research amongst ethnic minority groups because as well as being informants in their own right they are 'also gatekeepers to further informants, potential interpreters and assistants in the interpretation of culturally specific issues'.[250]

Sampling

Qualitative inquiry using key informants focuses in depth on relatively small samples, selected purposefully, and guided by the research question itself.[251] Individuals are selected strategically on the basis of their specialised knowledge,[252] the selection representing 'non-probability or information rich sampling'.[242] Pragmatic considerations place constraints on the number of informants to be interviewed and informant 'feedback' assists in the 'progressive restructuring' of the choice of subsequent informants and the content of interviews.[247]

The aim of the sampling strategy for key informants was to incorporate a broad range of experts with particular involvement with African communities or with expertise in, or responsibility for, the medical or social aspects of HIV. Tremblay refers to this technique as 'a focused use of key informants' in which sampling involves a search for those 'who might be expected to have specialised information on particular topics'.[247] It became clear during the observation phase of data collection that the process of diagnosis and care involves a number of different agencies, statutory and voluntary. In addition, African people may have particular needs relating to immigration and housing issues that might add another layer of professional involvement to their care.

Thus, a wide range of professionals were approached, for example medical practitioners, as well as those working for voluntary agencies with specialist involvement in HIV. The sample included informants who worked closely with African people 'on the ground' such as a social worker, as well as those whose involvement is further removed but, by virtue of their professional position, make a considerable impact on the management and delivery of HIV services because they are key decision makers in the allocation of financial resources.

The final sample comprised 12 key informants identified in a number of ways. Some were known to the researcher from her own knowledge of the field and medical contacts within the area. Others were identified as the project progressed

and in consultation with key informants during their interviews. This latter has been described as 'snowballing or chain sampling'[253] where informants 'provide the researcher with introductions to other informants'.[252]

Recruitment

For the majority of respondents, initial contact was made by letter explaining the purpose of the study and their anticipated involvement if they agreed to participate. In accordance with the requirements of the research ethics committee, a participant information sheet was included. In a small number of cases, where there was a pre-existing professional relationship between researcher and participant, initial contact was by telephone. In the case of one key informant, first contact was made through personal introduction by another participant.

Although some researchers suggest that gaining access to professional elites may be problematic,[246;254] access was relatively easy for this study. It is possible that this was because the researcher was known to be a doctor; particularly with fellow health professionals, both researcher and researched are bound together by professional identity.[255] Certainly in this study, once confidentiality was assured, access to key informants was unproblematic and all those who were approached agreed to participate.

The interview

In depth interviews were conducted with 12 key informants, each being conducted at their place of work and lasting between 45 minutes and 1½ hours. In addition to an information sheet prior to the meeting, a verbal explanation of the study and the interview process was given before proceeding, with interviewees also being given the opportunity to ask questions. This process enabled the interviewee to be set at ease and for a measure of rapport to be established prior to the interview. The participant was then asked to sign a

consent form and for their permission for the interview to be recorded. All agreed to this, having been assured of anonymity and confidentiality.

The interview topic guide

The interview topic guide (see Appendix 6) was designed to cover the key substantive areas of HIV testing and management, and barriers to care and testing. As well as issues relating to HIV, it sought to cover areas relating to immigration and social care. It was used primarily as an *aide memoir* to ensure the same topics were discussed in all the interviews.[256] As the interviewing proceeded it became less necessary as the researcher became more familiar with the areas to be covered. The topic guide began with background information about the informant's own involvement and experience of working in the field. Beginning with questions that the interviewee can answer easily before proceeding to more difficult or sensitive topics is known to be a helpful approach.[257] Rather than covering the topics in a rigid order, the interview was conducted in a flexible way, attempting to cover the desired areas within the natural order of the conversations.

The key informants were from a wide range of backgrounds and it was therefore important that the topic guide be designed to allow respondents to focus on issues salient to them whilst also attempting to elicit views on certain issues that were important to the researcher.[258] The relatively open-ended nature of the interview process allowed room for discussion of issues raised by respondents and previously unanticipated by the researcher. In an iterative process, where it seemed appropriate, such new areas of insight were added to the topic guide for subsequent interviews.

3.3.3. African participants

The next phase of the fieldwork, informed by the key informant interviews, comprised in-depth interviews with black African people living in the Bristol area. The aim of these interviews was to explore perceptions of HIV and access to

testing, and to elicit the experiences of African people living with and being tested for HIV and the meanings they give to their experiences. The interviews provided an opportunity to hear first hand accounts from those with a story to tell.

In-depth interview methods

In qualitative interviews the researcher is concerned with 'understanding and describing a social and cultural scene from the emic, or insider's perspective'.[243] Understanding why people behave in certain ways and exploring the relationship between beliefs and behaviour is, as Helman has noted, particularly amenable to qualitative inquiry,[259] with interviews offering 'a rich source of data which provide access to how people account for both their troubles and good fortunes'.[214] Interviews in qualitative research may be structured, unstructured or semi-structured. In a structured interview, the researcher asks the same questions in a precise manner to numerous individuals, offering the same set of possible responses to each individual. In contrast, unstructured interviews are similar to guided everyday conversations where the researcher has one or more topic areas that are probed whenever the opportunity arises.[260] Although the terminology does vary, this study used what will be referred to as in-depth interviews using a semi-structured schedule. This means of data collection is more often used in the context of health care, and uses a loose structure consisting of a number of open-ended questions that define the area to be explored.[257] The informants are encouraged to express their views at length and in their own terms, maintaining a conversational tone to achieve a more 'naturalistic' style of interviewing.[220] The interview comprises broad topics that the researcher wishes to know about, without relying upon fixed questions, thus giving freedom to the interviewee to introduce new issues for discussion that the researcher may not have anticipated. The skill of the interviewer is to encourage the participant to speak as fully and freely as possible, with the interview being interactive, responsive to the language and the concepts used by the interviewee, and maintaining flexibility.[244] The researcher uses a range of probes and other

techniques to achieve a depth of answer that goes beyond the initial response, which might be relatively superficial. The in-depth format permits the interviewer to obtain a deeper and fuller understanding of the participants' meaning and 'to explore fully the factors which underpin participants' answers: reasons, feelings, opinions and beliefs'.[261] To achieve this, in-depth interviews require intimacy and in this respect they resemble the forms of talking found between close friends. Yet there are important differences; unlike talk between friends the researcher is seeking 'deep' information for some other purpose.[262]

In discovering the interviewee's own framework of meanings the researcher seeks to 'avoid imposing her own structures and assumptions as far as possible'.[257] Thus, good questions in qualitative interviews, according to Patton should be open ended, neutral, sensitive and clear to the interviewee.[251]

The 'researcher as research instrument' [257] shapes the interview, the data and the interpretation by her own worldview in conjunction with that of the respondent. The researcher usually listens more than she talks, encouraging participants to express their own ideas and to speak in their own terms. She is an active listener, reflecting upon what is being said and engaging in the 'interpersonal drama'[263] of the interview. Knowledge of the social world is actively constructed as a collaborative process entered into by both researcher and respondent.[263]

In-depth interviewing fits well with grounded theory approaches because it combines the necessary flexibility to allow themes to emerge naturally, with sufficient interviewer control to direct conversation towards conceptual gaps or issues that require further exploration.[233] It is an evolving and iterative process in which questions in later interviews are shaped by themes emerging from earlier interviews, with 'conceptualization and reconceptualization' of the research as it proceeds.[264] Flexibility in the topic guide is therefore essential, but this flexibility does not negate the need for at least some element of researcher control within the interview.

There are difficulties with in-depth interviews in which interviewee and interviewer become 'peers' or even 'companions'.[265] Hammersley and Atkinson point out that non-directive interviewing is in itself a form of social control which shapes what people say.[220] Where the researcher asks very few questions and maintains a minimal presence, this can 'create an interpretive problem for the interviewee about what is relevant'.[214] Patton outlines three strategies for maintaining control of the interview: knowing the purpose of the interview, asking the right questions to get the information needed, and giving appropriate verbal and non-verbal feedback.[251]

Thus, the interviews in this study were a form of 'directed conversation' in which there was a loose structure defined by a range of topics to be explored, shaped both by the literature and the key informant interviews. Whilst there has been limited research into sexual behaviour of ethnic minority groups, there has been even less specifically focusing on HIV in African people in the UK. The author is not aware of any research into the specific area of HIV testing in African people in a setting outside of London. Thus, in-depth interviews were particularly well suited to researching this previously unexplored area[244] with the added benefit of being especially appropriate for exploring complex and 'sensitive topics' including sexual history and practice, immigration and culture for example.[244;266;267]

Methods other than in-depth interviews were considered but were not thought to be as appropriate. A questionnaire for example would not have given the depth of information sought, as questions would have necessarily been selected on an arbitrary basis influenced by the researcher's own judgement about important issues for this previously unreported group of respondents. The method of in-depth interviewing ensured that informants' experiences would not be limited to fixed choice responses or pre-determined variables. Further, using in-depth interviews with African participants enabled unique insights into complex social behavioural questions. Kesby argues that sexual decision-making is 'relational', and that for interventions to be sensitive to the relational nature of sexual

decision-making within Britain's African communities they require detailed knowledge of the shared belief and norms specific to this community, which is itself rather diverse.[28] In-depth interviews are uniquely valuable in understanding complex lifestyle and cultural aspects of HIV which can help in the development of appropriate interventions and are particularly valuable in the context of community based initiatives that target difficult to access populations.[201]

The methodological underpinning of this series of interviews with African participants shares some common features with the key informant interviews. As has already been noted, key informant interviews produce more than neutral or purely factual accounts. Similarly, the African participant interviews produced accounts which were actively constructed to portray particular worldviews, both shaped and interpreted by the researcher, her own worldview, ideas and experiences. To some extent the interpersonal and interview dynamics were different. Although the key informants tended to be less emotionally engaged with the issues under discussion, this was not exclusively the case and for some there was a cathartic aspect. Many of the African participant interviews were highly emotionally charged with disclosure of painful life events. For the researcher, the way in which these interviews were conducted required great sensitivity, care and respect. They tended to be less structured, longer and emotionally demanding for the researcher (see 'Reflexivity' on page 234). As called for by Kesby et al[28], the in-depth nature of the interview enabled the sharing of life stories, of particular interest being the sexual life histories that set 'individuals self-reported actions within a wider social context that helps illuminate their causation ... (and) the important question of changing contexts, relationships, discourse and behaviours before and after migration'.[28]

Sampling

Qualitative research uses non-probability sampling in which the focus is on small samples of people 'nested in context' and studied in depth.[207] The aim is not to

produce statistically generalisable findings but rather to employ a sample size and strategies that are guided by the aims of the project. The current study incorporated elements of a number of qualitative sampling strategies as the research progressed. Such 'waves of subsequent sampling decisions', according to Marshall and Rossman, are a common feature of much qualitative research.[246]

The study employed purposeful sampling, in which the researcher 'actively selects the most productive sample to answer the research questions'.[268] Sampling for maximum variation was used to identify a range of African participants, not to 'focus on similarities that can be developed into generalisations but to detail the many specifics that give the context its unique flavour'.[269] In his discussion of the various sampling strategies that may be used in qualitative studies, Patton asserts that maximum variation means that any common patterns that emerge are of particular interest because they are likely to be capturing the core experiences and the central shared aspects of varied situations.[251]

The African participants were not a homogeneous group. Much epidemiological research in the UK groups a diverse range of people under the term 'black African', neglecting to account for the heterogeneity in nationality, ethnicity, religion, socio-economic status, gender, age, and length of residence in the UK, for example.[28] The current study recognised this and sought to explore a diversity of opinions, experiences and backgrounds.

Maximum variation sampling was attempted by trying to find as many respondents as possible from a variety of countries, economic and immigration status, and prior and current experience of HIV. The aim was to include: men and women; individuals from a range of countries in sub-Saharan Africa; respondents in contact with and not in contact with medical or other services; those with settled immigration status and those for whom immigration remained a source of uncertainty and anxiety; and people who had a range of experiences of HIV testing. The sample selection specifically sought to include those who had

been tested and who were known to be living with HIV, those who had been tested and for whom the result of the test was known to be negative, and participants who had not been tested and whose HIV status was therefore unknown.

According to Lincoln and Guba, using a maximum variation approach can help to develop theoretical sampling.[269] Theoretical sampling occurs when the data already collected lead to strategies for future data collection based on the developing theory.[236] Sampling for African participants was to some extent theoretically guided. Being an iterative process, later sampling decisions were shaped by preliminary analysis and theoretical concepts emerging from earlier interviews. For example, it emerged that further sampling would need to be directed towards male respondents who had not been tested for HIV and whose status was therefore unknown, in order further to explore ideas around gender inequalities, power in sexual relationships and particular gender-related barriers to HIV testing.

Recruitment for this study was always expected to be challenging and it was necessary and fruitful, on occasion, for the sampling to be opportunistic. As Patton describes, fieldwork can often involve 'on the spot' decisions about sampling and taking advantage of unforeseen opportunities and making the most of whatever unfolds.[251] This was particularly the case when key informants offered to introduce the researcher to respondents, or when participant observation led to an introduction to a potential respondent. On two separate occasions, interviews were conducted with respondents who did not fit the selection criteria. This arose from the researcher being introduced to members of an African women's HIV support group. The 'gatekeeper' had worked with the two women in question but had not realised that they were of Jamaican descent. It was not until the interviews were underway that the country of origin information became known. However, the 'unforeseen opportunity' was grasped, and a rich comparison with African participants was obtained, further informing the analysis of the data although not formally included in it.

To strengthen the credibility and completeness of the analysis, the sampling strategy sought to include both confirming and disconfirming cases.[270] In particular, it was important to include those who had been tested and were found to be HIV negative because they might hold disconfirming views on the barriers to HIV testing. By definition, they had not been tested as a result of symptomatic, late HIV disease as was thought to be the case for many of those known to be HIV positive. Rather, they had come forward for testing for other reasons and it was possible, therefore, that they might have very different perceptions of HIV testing.

The final sample included 26 participants, comprising 11 women and 15 men from 11 countries. 14 were known to be HIV positive, seven were HIV negative and five did not know their HIV status. The gender, ages and country of origin of the participants are shown in Appendix 3.

Recruitment

This research is investigating a specific sub-group of the UK population that is relatively 'hidden'.[271] For a number of reasons, particularly issues relating to immigration, African people might not be in contact with services and some may be reluctant to engage with those they see as potentially representing authority. In addition, the nature of the subject matter was sensitive and often taboo. Those who knew themselves to be HIV positive had, for the most part, disclosed their status to very few people, if any , outside of their professional carers. For all these reasons, it was extremely challenging to identify appropriate individuals to approach to take part in the research and the task was a major component of the empirical work, consuming large amounts of time and resources. It was necessary to be flexible and creative in the approaches taken. It was also important to maintain tenacity and equanimity, and not to be easily discouraged. Given the nature of the research and the 'hiddenness' of the population to be sampled, the strategies adopted to accumulate the sample were very diverse and relied to a large extent on determined investigation and networking. It was

vitally important to build trust from an early stage, to be invited into 'closed' groups, and for key informants (who acted as gatekeepers to potential participants) to believe that it was safe to allow the researcher access to Africans known to them.

Participants known to be HIV positive were, on the whole, more easy to identify. Such respondents were, by virtue of their known health status, in contact with one or more health, social or voluntary service. An initial invitation to participate came from an appropriate gatekeeper. This was usually a social worker, clinician or a worker from within the voluntary sector. In all cases the gatekeeper first gave verbal and written information regarding the study to the potential participant, before seeking permission for the researcher to make contact.

A wide range of strategies was employed to recruit other participants. The early participant observation had given the researcher a broad knowledge of the potential sites and contacts. Community groups, colleges and individuals known to be associated with African communities were contacted by telephone and/or letter. A great deal of time was spent fostering good relations and seeking access to networks and to individuals, a task which has been recognised as particularly demanding when involving cross-cultural studies.[272] She attended community events in areas of the city known to have a higher proportion of African residents, taking the opportunity to publicise her study. She spent time in a bar and restaurant frequented by West Africans, attended African music events and was invited to Zimbabwe Independence Day celebrations. The time and energy invested in these activities sometimes yielded little in the way of recruitment but contributed valuable insights into the communities of interest. Posters in GP surgeries and further education colleges did not bring any potential interviewees to light. A potential breakthrough came with the researcher being given access to a community radio station that was broadcasting for one month into an area of the city known to have a high density of African residents. *Ujima FM* sought to 'explore culture through radio' and had a number of programmes designed to be

of particular interest to Africans. Broadcasting live during one of these programmes, the researcher was able to publicise the study and give contact information. She also recorded a short item that was subsequently broadcast on a number of occasions during the month.

None of these events or strategies in themselves directly brought forward participants. However, they did eventually yield results through the links, networks and personal contacts established. It was perseverance and the building of relationships of trust that eventually yielded access. As Power has noted, the qualitative researcher as ethnographer or participant observer can nurture and forge 'trusting and sensitive links with respondents'.[273] As a result, a number of introductions were afforded to the researcher. These often required extensive follow-up for those willing to participate to actually be interviewed. It eventually emerged that the most effective way of contacting potential interviewees was by mobile phone; without exception all respondents owned one. Many lived in accommodation where there was no landline, particularly asylum seekers in hostel accommodation. Even so, making contact and keeping appointments was problematic. Some worked varying shift patterns and appointments were often changed several times. Time keeping presented a particular problem - interview arrangements would be forgotten or the respondent would be late. It was not uncommon for the researcher to attend at the agreed time and place to find that the interviewee had left shortly before as they had been called into work or had made another arrangement. The researcher ensured that she phoned on the day of the interview to confirm the arrangements. A certain amount of time was saved this way but missed appointments continued to be a feature of the fieldwork. Often the interviews could be rearranged and were subsequently conducted. Where there were repeated changes or three missed appointments, further attempts to interview the participant were abandoned. This happened on two occasions.

A number of additional strategies were adopted in order to aid recruitment. As well as posters for display, the researcher produced a number of attractive cards

containing brief information regarding the study. At the end of each interview, consideration was given to the possibility of using the snowballing technique; gaining access to potential participants who were known to an interviewee, and who may themselves meet the sample criteria. However, only a very small minority of respondents were recruited using this method. As mentioned above, most HIV positive respondents had not disclosed their status outside of their immediate family, and occasionally to no one outside of the medical profession, rendering snowballing, for the most part, completely inappropriate. The technique was potentially more feasible for use with respondents whose HIV status was unknown, and for those who were HIV negative. However, there remained an understandable reluctance to introduce the researcher to others. This appeared to be related to a reluctance to disclose the fact of their test for fear that assumptions would be made by others about the nature of their sexual activity and particularly a fear of being labelled 'promiscuous'. However, when appropriate, 'business cards' were given to the interviewee to pass on to suitable friends or family and the strategy was successful in facilitating recruitment of a small number of subsequent participants.

The researcher became aware during the course of the study that many potential participants were struggling financially. One of the difficulties in making interview arrangements was the long hours and overtime shifts that participants were engaged in. A decision was made to pay participants a sum of £20 to reimburse them for their time and costs associated with attending the interview. It was felt that this was a reasonable payment without being an undue inducement to take part in the research. The Research Ethics Committee that had given approval for the study agreed to this proposal.

The interview

Interviews were carried out in a wide variety of settings. It was crucial to be flexible enough to accommodate the needs and concerns of the participants. Some felt more comfortable in their own home (often bed-sits or hostels) while

for others, issues of confidentiality meant they wished to be interviewed outside their home. Most of these interviews were conducted in either a hospital clinic room or a university room. Others preferred to meet at the offices of the Terrence Higgins Trust and one HIV positive man wished to be interviewed in a public house. In each case the researcher worked with the participant to identify the most appropriate location.

Each interviewee had previously received a verbal explanation of the study and interview process. Before the interview began, each participant was given an information sheet and the opportunity to ask questions. The researcher ensured that the participant understood the nature of the study, was willing to participate and had received satisfactory answers to any outstanding questions. They were also asked to complete and sign a consent form. Each participant was given the assurance of confidentiality and anonymity and given this, all were willing for the interview to be recorded.

Interviews lasted between 45 minutes and 2 ½ hours, with further time at the end of the recorded interview for more informal conversation. The interviews with HIV positive participants were amongst the longest interviews primarily because, as discussed below, these included detailed exploration of issues related to living with HIV.

An in-depth interview passes through a number of stages and the researcher's task is to take the interviewee down from a social to a deeper level at which they can focus on a specific topic. Towards the end of the interview, the researcher signals the return back to the everyday level and this process needs to be fully completed before the researcher leaves the participant, who should be 'left feeling well'.[261] Throughout the current study, this task was a primary concern. During the course of some interviews, the researcher and interviewee covered harrowing ground. Many interviews involved an intensely painful and emotional journey. Not only was it important for the researcher to be extremely sensitive to this during the formal 'interview stage' but also after the recording

equipment was switched off, intentionally spending time with the participant and easing them back into the everyday and ensuring well being. A reflexive discussion of these issues can be found in section 6.3.2.

Interview topic guide

As with the key informant interviews, a flexible topic guide was used to help ensure consistency in the areas covered in the interviews whilst allowing room for the participants to discuss issues that were of importance to them.[261] The topic guide (see Appendix 7) drew upon issues identified both from the literature and from the key informant interviews. A number of apparently important areas of concern were raised by the key informants including, for example, African health beliefs, disclosure and confidentiality and the fear of being perceived as racist if targeted testing were adopted. These were included in the African participant topic guide, which was also influenced by some anecdotal accounts relayed during the course of participant observation and other informal discussions.

As there has been little empirical work published on HIV testing, particularly research within African communities, it was important to make the process of data collection as exploratory as possible, attempting to encourage respondents to provide their own accounts of their situation and to raise the issues that were important to them.

As the fieldwork progressed, the topic guide was modified to take account of issues that had arisen in earlier interviews but not initially considered to be of great importance. For the participants who were known to be HIV positive, the experience of living with HIV was an important area that they wished to discuss and on which they wanted to be heard. Although the primary aim of the study was to consider issues relating to HIV testing, in interviewing individuals known to be living with the virus it was inevitable that broader issues relating to HIV would be a prominent part of the discussion, particularly because in-depth

interviews lend themselves to interviewees expanding the content of the interviews.

In any case, with due regard for the insights of symbolic interactionism discussed earlier, it was important both to explore the symbols and meanings attached to HIV and HIV testing, and to consider how this might or might not be shared by people with different life experiences. If the knowledge of being infected alters the perception of testing (so that with hindsight interviewees attach a different understanding and meaning to testing) the question then arises as to whether an individual might be more or less likely to be tested for HIV if they *considered the possibility* that they might be infected. This question is important of course, for pragmatic reasons. As Snape and Spencer accept, funded research often requires that research findings can be translated into policy planning and implementation.[203]

Thus, the researcher followed the respondents into this area and explored issues with them, later adapting the topic guide so that an amended topic guide was used in interviews with participants known to be HIV positive.

It also became apparent as the fieldwork progressed that some of the most important issues for respondents were intimately bound up with their 'life story' and that the topic guide could make up only a small part of the respondent testimonies. This lends weight to the appropriateness of the method selected. Had the items on the topic guide formed the basis for a fixed choice questionnaire a distorted, or at least a very limited picture of the realities for this participant group would have been the result. Kirk and Miller (1986) point out that most validity errors arise from asking the wrong question and therefore qualitative techniques can be said to have almost 'automatic' validity given the diffuse and flexible nature of the data collection.[274]

3.4. Data management and analysis

The methodological principles underlying the management and analysis of data arising from both key informant and African participant interviews were similar and will be described together in this section. Particular differences in emphasis or practice will be highlighted.

The process of analysing qualitative data is complex and iterative, escaping easy abstract description.[275] It relies on both critical and creative thinking, and has been described as both 'science and art'.[251]

The computer software package Atlas-ti,[276] a programme designed for use in qualitative data analysis and based in part upon grounded theory methodology, was used to assist in the process of conducting a thematic analysis, drawing on the principles of constant comparison.[236] Computer packages can be of great help in enabling all the data relevant to each analytical category to be identified and examined, with each item in turn being checked or compared with the rest of the data.[277] However, any software package can only assist, it cannot perform the analysis; perceiving a link between theory and data is the preserve of the researcher.[277]

Transcriptions

To ensure accuracy and detail of information,[278] all interviews were digitally recorded using a minidisc recorder with external microphone. It is possible that interview conversations might be inhibited if the informants are nervous about being recorded. However, it was felt that as well as benefitting the analysis and interpretation of the data, recording would ease the conduct of the interview because it would allow the conversation to be the primary focus rather than having to write down what was said. For the African participant interviews good quality recordings meant that exact words and phrases, sometimes unfamiliar to a non-African researcher or clerical assistant, could be more faithfully transcribed and greater familiarisation with the many different accents be gained.

All discs and transcripts were anonymised for confidentiality purposes and stored securely. The recorded data were fully transcribed as an accurate recording of the words spoken, including interruptions, pauses and laughter. A clerical assistant initially prepared transcripts using the transcription software package 'Transcriber'[279] according to a standardised format and instructions for indicating overlapping speech, emphases, interruptions and pauses. These transcripts were then edited and corrected by the researcher by replaying the recording and comparing these with the prepared transcript. On occasion, details of actions accompanying the conversation were added, based on the researcher's knowledge of each interview and her fieldnotes. This checking and correction was particularly important for the African participant interviews. Both clerical assistants involved in transcribing these interviews appeared to have considerable difficulty in 'hearing' or understanding the sense of what was being said by the participants. Presumably this related to unfamiliarity with accents and phraseology as digital recording had ensured that sound quality was high. In any case, such checking by the researcher aided familiarisation with the data.

Fieldnotes and interview summaries

Following a preliminary review of the transcript and fieldnotes a short summary of the interview, together with social, demographic and morbidity characteristics was prepared for each interviewee. This served to keep a record of key characteristics for the purpose of further sampling and, most importantly, provided a summary of the main concepts, themes and questions arising from each interview. This process prompted deeper reflection and provided orientation for subsequent interviews. The preliminary fieldwork observations were particularly useful for illuminating contextual factors and the detailed notes written by the researcher immediately after each interview were considered to be data in their own right, aiding the process of interpretation and reflexivity.

The summaries also enabled early comparison across respondents, aiding the development of conceptual codes for analysis (see below). Additionally, as the

analysis progressed, they served as a contextual reminder of the respondents' whole narratives, as an individual's story becomes fragmented by thematic analysis across cases.

Data analysis

Analysis drew on the principles of grounded theory and was intertwined with data collection in a cyclical and iterative process. Most of the African participant interviews were conducted after completion and interim analysis of the key informant interviews. Analytical insights from the key informant interviews thus shaped the questioning during the African participant interviews, as the earlier African participant interviews shaped later ones.

The key informant and African participant data were handled separately for coding purposes, although the methodological principles used to analyse the data sets were similar and the analysis of each necessarily informed the other. The central concerns were with coding for patterns and themes, inductively identifying analytical categories that emerged from the data. The emphasis within the analysis was to represent the range of perspectives and experiences, using rich description, building concepts and theoretical ideas from the ground.

The intertwining of data analysis and collection of key informant and African participant interviews was almost inevitable. The intention had been to conduct key informant interviews prior to fieldwork amongst African participants. However, as noted elsewhere, the researcher responded flexibly when gatekeepers introduced her to potential interviewees and there was some overlap of data collection for the two groups. Later key informant interviews were therefore to some extent shaped by African participant interviews because for the researcher 'in the field collecting the data, it is impossible not to think about what is being seen and heard'.[277] Despite this intertwining of data collection and analysis, there was also a more formal identifiable process of analysis that occurred when the researcher finally left the field at the end of the African participant interviews.[210;277] It was during this stage that a more detailed analysis

took place, involving a search for more complex patterns and the formulation of more general and abstract expressions of the categories, with further theoretical reflection and particular concern for the interconnections between categories.[280]

Coding

Coding represents a key step in the process of analysis and has been described as 'the process of categorising and sorting data', with the codes themselves serving to 'summarize, synthesize, and sort many observations made out of the data'.[280] Strauss and Corbin describe coding as the 'central process by which theories are built from the data'[237] with coding, at differing levels, providing the link between data and conceptualisation.[280]

Open coding

Open coding refers to the process of 'breaking down, examining, comparing, conceptualising and categorising data'.[237] In the current study this involved scrutinising the transcripts in great detail, with each being read several times. The first reading enabled the researcher to get an overall feel for the issues covered and allowed a short descriptive summary of each individual interview to be written. Next, a detailed line-by-line coding of each transcript was carried out. Segments of data: sentences, phrases, and paragraphs, were assigned codes according to the meanings they contained. Initially codes were highly descriptive and derived directly from the data. After the first few transcripts had been coded, an initial 'list of codes'[207] was generated with the intention of displaying existing codes and noting those that were recurring. This made it possible to begin the process of moving beyond mere description of the data to the use of more conceptual labelling in which the number of codes was reduced (for example through combining similar codes), generalities were drawn and segments of text assigned the same code were compared for content within and across transcripts.

As data collection and analysis continued, the coding list was continually refined to take account of new themes or sub themes within broader codes as they emerged. A key element in the analysis was the writing of memos relating to the codes and emerging concepts, elaborating the data and facilitating the development of more abstract concepts.[280] Matrices displaying the occurrence and co-existence of codes were also constructed. This is a useful way of presenting the data in a condensed form to gain an overview of the information, enabling an exploration of patterns in the data and according to respondent characteristics such as gender or country of origin.[281]

Axial coding

Whereas open coding involves the gradual building up of categories out of the data, 'second level' or axial coding moves the analysis beyond the stage of merely identifying recurring ideas to finding connections between them. Strauss and Corbin refer to 'a set of procedures whereby data are put back together in new ways after open coding, by making connections between categories'.[237] In this research 'open' and 'axial' coding were not completely distinct phases, rather the two processes merged, with axial coding occurring as a natural progression from open coding. The coding list was used to develop a coding frame in which codes or concepts that referred to similar ideas or events were grouped to form categories that had a higher degree of abstraction. Codes within each category could then be explored to establish the properties and dimensions of each category. Hypothesised connections were also made between aspects of individual categories by considering codes according to their 'type'[207] for example if they represented a process, an outcome or a motive for a particular behaviour.

Descriptive accounts

Description was also a central feature of the process of analysis because it 'forms the basis for more abstract interpretations of data and theory development'.[237] Descriptive summaries of data and themes were prepared. This involved

retrieving from within and across respondents, extracts of data sharing the same code, and composing detailed summaries of the content of each code. In this way it was possible to double check that data assigned the same labels did in fact relate to similar phenomena, drawing attention to codes that were shared across interviews and identifying those that were unique to particular cases. The code summaries were considered against the context of each interview, exploring underlying differences and similarities, and provoking questions to be further explored.

Throughout the analysis an attempt was made to keep track of emerging theory by representing this as a diagrammatic conceptual framework, incorporating links to memos that expanded on the theoretical reflections and formed the basis for the development of hypotheses.

Presentation of findings

In the presentation of findings (Chapters 4 and 5) it is not feasible to present all the data collected. The provision of one or more quotations in support of a particular theme or sub theme is a common form of confirmation, also known as 'source triangulation'. To avoid the claim of some critics that qualitative researchers could select an unfair and unrepresentative collection of quotations, it is important to give an account of how the quotations are selected for presentation. In this study three main criteria were used in the selection of quotations: that the quotations should be representative of the theme, they had to be articulate and/or concise, and to avoid excessive selectivity in reporting data, they had to represent an informant who had not been selected very frequently elsewhere in the analysis. The quotations presented in Chapters 4 and 5 are copied from the transcripts and represented as they were spoken. The quotations have been 'cleaned' only to the extent that words and phrases such as 'you know' and 'ah' have been omitted if they did not alter the meaning of quotations, in order to improve the flow of the narrative. Where non-essential sections have been omitted this is denoted by '...'. In appropriate instances, a bracket phrase [ ]

written by the author has been included to clarify a point that might otherwise be ambiguous. When quoting an informant an identifier has been added so that all quotations can be traced back to the original transcript, to aid transparency and provide an 'audit trail'.

3.5. Concluding comments

This chapter has discussed the methodological approach and methods adopted for this study of professionals' and Africans' views of the barriers to HIV testing in African communities. Whilst it has sought to engage with the philosophical underpinnings of qualitative research methods, it has shown that this study is not welded to one philosophical position, but rather has an appropriately pragmatic approach, choosing the theoretical strands and empirical methods that are best suited to the research questions.

The next two chapters present the research findings, beginning with the key informant interviews with professionals in the field of HIV in African communities.

CHAPTER 4. THE VIEWS OF PROFESSIONALS

4.1. Introduction

This chapter presents an interpretive account of the data from the in-depth interviews with professionals working in the field of HIV. Participants were from a range of professional backgrounds in health and social care, and worked both in statutory and non-statutory settings. Thus no term was able fully to encapsulate this group, and for the purpose of this study they are referred to primarily as 'professionals' whilst also being recognised as 'key informants'. Details of the professional role of each participant are given in Appendix 2.

The interviews provided contextual background and outlined the range of services currently available. They provided a backdrop to the interviews with African participants and served to map out the key issues and the potential barriers to the uptake of HIV testing. However, far from being a neutral and objective source of information, the key informants represented a range of perspectives and opinions related to their differing social, professional and organisational affiliations, which were further influenced by their experiences and relationships with African people.

These professionals had various degrees of personal involvement with African people. To a greater or lesser extent throughout the range of interviews, it was apparent that there had been emotional engagement with the personal stories of individual African patients. In the majority of cases at least some of the interview was shaped by relationships with one or more African person whose personal account had been at the same time both illuminating and shocking. As such, the data from interviews with professionals is closely bound up with the African participant data; informants sought to understand the issues faced by African people and to interpret the HIV testing and treatment behaviour of African people in the light of their perception of the 'African worldview.'

In this chapter the range of themes emerging from the interviews with professionals will be presented, drawing out the different perspectives displayed by the range of experts represented in the interviews. The chapter begins with a discussion around service need and current provision, before moving on to consider professional-African relationships. It discusses African perspectives, as the professionals perceive them, prior to considering some of the motivations, beliefs and feelings operating beneath the professional veneer. Priorities and various agendas are then discussed, before concluding with a consideration of the way ahead and the role of primary care.

To illustrate the themes and perspectives, selections of quotes along with participants' identifiers will be given. The identification codes indicate the participant's gender and the professional group to which the person belonged, as summarised in Figure 10 below.

Figure 10: Professional interviewee identifiers

D = Doctor	H = Sexual health advisor
M = Specialist midwife	P = Primary Care Trust employee
S = Social worker	V = Non-statutory sector employee

4.2. The changing scene: the need to respond

The increase in new diagnoses in African people

In response to a general question about the nature of service provision and need, the respondents offered views about the extent of the HIV positive population within the research setting. It was widely agreed that there had been a marked increase in the number of African people who had been identified as HIV positive.

> *At the end of 1998 our service was very heavily gay men... We are now getting increasing numbers of people from other*

> *countries, usually Africa, the largest proportion are sub-Saharan Africa.* **D1female**

A number of respondents remarked upon how dramatic and recent the increase in the number of Africans infected with HIV had been, referring to the strain it placed upon the provision of services in a setting with little experience of HIV work with African communities.

> *In the last couple of years there's been a massive change in the new cases presenting from sub-Saharan African countries particularly amongst refugees and asylum seekers, very very noticeable, put enormous pressures on the treatment services and the drug budgets as well.* **P2female**

It was generally felt that whilst there are some similarities with African communities based in London, there are particular issues outside of the capital because African communities tend to have a looser structure and services are not provided in the same way. A number of respondents pointed out that it was not sufficient only to translate existing services from the London experience.

> *Although they've got a lot of experience in London, actually it isn't directly transferable because the communities aren't developed in the same, they don't have the same structure in Bristol, they are much looser groups of people, so actually there aren't the visible ways of making contact and beginning to work with the communities.* **P1female**

Late presentation of disease

The nature of the presentation of HIV within African communities was an important area of discussion in most interviews. All but one (non-clinical) respondent volunteered that African patients generally present at a later stage of disease progression than the indigenous population. There was agreement that African people come forward for testing later, and often testing is not carried out until the patient is symptomatic. Many are diagnosed as hospital inpatients, admission having been precipitated by symptomatic (and often AIDS-defining) disease.

> *My feeling is that that they [Africans] present late with a late*

> *stage disease. I feel that they have a higher mortality... they would often present ...with advanced disease and my feeling is that they have required more hospital in-patient care than the corresponding cohorts of known HIV positive patients who we follow-up.* **D3male**

For African patients, more frequently than for white patients, even when hospital admission is avoided late presentation often results in an immediate need for treatment with antiretroviral therapy. The need to start medication immediately can be especially burdensome for an individual who has just been diagnosed and is attempting to deal with its psychological impact.

> *A lot's going on at that early stage whereas before people have been diagnosed for longer, and some of them, men I'm working with, white UK men, haven't even started combination therapy yet.* **S1female**

Professionals associated late presentation of disease with treatment sometimes being less effective and some damage being irreversible. They felt that late presentation, coupled with the marked increase in HIV infection seen in African communities, made it important to explore ways in which the situation could be improved, and these will be considered later in this chapter.

4.3. Relationships with Africans: compassion, advocacy and frustration

The next important theme to emerge from the professionals' accounts was the nature and quality of relationships with African people. With the exception of two informants, whose work did not involve direct contact with individual Africans, the accounts were grounded in direct experience of relationships with African people. The degree of involvement varied with professional role and with the HIV status of the African person. Some participants had provided care and support to individual Africans over an extended period of time and the interviews were illustrated throughout by examples of particular patients and their stories. The relationship between professional and patient or client was considered a significant factor not only in the ongoing therapeutic management

and care of a person infected with HIV, but was also regarded as crucially important at the time of testing; the decision to undertake an HIV test may itself be positively or adversely affected by the relationship between African and professional.

4.3.1. Compassionate concern: professional care and personal involvement

Compassion and empathy

One of the most notable aspects of the relationship between professional and African to emerge from the interviews was the extent to which working with African people had impacted upon the professionals at a personal level. Commonly there was emotional involvement in the stories and experiences of at least some of the African people with whom they had worked, with discourses around these experiences arising spontaneously across the professional spectrum.

Sometimes this was seen in an empathetic reflection on the situation that African people found themselves in. One consultant spoke of what he saw as the tragedy and sadness of dying far from home, and how he personally would feel.

> *I felt very sad for them because I would hate to die away from my family and friends and country – a slow lingering death.*
>
> **D3male**

Although most informants worked with patients from a wide range of backgrounds and knew well the potentially devastating impact of a diagnosis of HIV upon any individual, there was common recognition of the particularly difficult circumstances faced by many African people. Many of the Africans with whom they worked had faced harrowing events in the past, often including brutality and sexual violence in their country of origin. As these stories were recounted within the interviews it was apparent that professionals felt a level of emotional engagement with their patients. The relationship, whilst being

'professional' was also intensely human and full of compassion with a clear attempt to understand and to support.

> *We had a woman from Burundi... Her family had been murdered in front of her, she was raped by a number of soldiers and there was a huge number of events, all of which were absolutely horrendous... She was dispersed over to Bristol. She had no friends, no family and there wasn't anybody that she felt she could tell... she was somebody we were all very, very concerned about.* **H2male**

The sense of being concerned for the welfare of African patients was repeated across many of the interviews. Professionals were keen to provide support, particularly in cases where non-disclosure of HIV status led to increased isolation. A number of professionals spoke of being flexible, providing a personal level of service that might provide at least a safety net for the African patient. This was seen across the board, not only in the non-statutory sector but also within the busy genitourinary medicine clinic where there was a real desire on the part of health workers to provide access to care and support, even if this meant going outside of their usual structures of care.

> *... making sure that they feel that even if there is no one else they have got to talk to at this stage they've got us. Or they can come back to the clinic or they can phone us up at anytime, that that's not going to be an issue.* **H1female**

Maintaining professional distance

There was undoubtedly a level at which the experts involved in the care of individual Africans became caught up in the personal drama of their stories and personalised it with reflections upon how they would feel in such a situation. However, for some there was also a deliberate attempt to retain a professional distance. Even this, on occasion, was presented as being in the best interests of patients. The same consultant who mused on how difficult it would be for him if he were to be ill and die in a foreign country, away from family and friends, saw benefit in maintaining distance. Getting too involved, and asking too many

questions might create further difficulties, especially around advocacy and provision of treatment to those of uncertain immigration status.

> *We are acting as the patient's advocate and matters of pleadings and if we felt that they were here illegally, or whatever, we may pass our views. So I don't tend to ask too much about it. I tend to like to know a broad-brush view, rather than specific details.*
>
> **D3male**

4.3.2. Protection, advocacy and justification: 'sometimes we can be a bit precious'

Advocacy

Closely linked to the compassion and personal concern shown by many professionals involved in the care of African people, was a strong desire to protect and to defend them, even to provide justification for their actions when they were criticised by others. Participants referred to the ways in which they advocated on behalf of HIV positive African people including writing letters to support immigration appeals, often with clinicians and other agencies working collaboratively.

There was often a feeling that the professional was taking the side of the African against the authorities: the hospital trust seeking to recover financial costs, or immigration services or other statutory agencies such as the Council's Housing Department. On occasion this took the form of direct intervention, sometimes deliberately undermining hospital policy. On other occasions it took the form of giving advice on how best to handle the system.

> *When I used to work at [Hospital] we did see a lot of women that were illegal immigrants, for want of a better word, refugees, and we used to have letters on their notes saying we have to get hold of the head clerical person to come and talk to them, because they shouldn't be receiving NHS care, which is like a real joke isn't it? What are they meant to do then? They are pregnant. But we used to get that on their notes, saying "please inform such and such when this woman arrives." And of course, we see them and inform them as the woman's going (laughs).* **M1female**

Health tourism

A number of informants raised the issue of health tourism - that is a person who knows they are sick deliberately coming to this country to access treatment from the NHS. Whilst it was felt not to be the majority, it was accepted by several participants that 'a proportion' of their patients might have come to the UK because they already knew they were unwell.

> *You wonder whether they've actually just come to this country because they knew they were sick. We don't know. We just don't delve too much.* **D1female**

Generally, the view of professionals was that for many Africans this was probably an inadequate explanation; experience with some African patients suggested that they had not even been aware of the existence of treatments.

> *I think sometimes we presume that people have come over for treatment, but they may well not realise that there are treatments available because it hasn't been at home.* **H2male**

Even when it was thought likely that health tourism might be taking place there was no criticism, but rather informants saw this as an understandable human response. This empathetic understanding and justification of the actions of African patients went even further. One informant considered reports he had heard of medication being sent home to treat family and friends.

> *Some centres report they have people who have care in several centres and send back the medication to their relatives... That's also an understandable situation.* **D3male**

The generally supportive attitude towards African people was shared by most, but not all informants. A participant from the Primary Care Trust was seemingly convinced that the increase in new diagnoses of HIV amongst African people was largely explicable by health tourism, relating this to the 'massive overspend' on the budget.

> *It is actually new people in the country or people who had known their diagnosis for some time and then had only chosen to be tested again and come into the treatment systems.* **P2female**

However, on the whole professionals attempted to justify or minimize the extent of health tourism. For the most part, clinicians did not see it as their role to become involved in what they saw as political decisions. They preferred to treat on the basis of need, so that anyone presenting to the HIV services would be given treatment and it is left to others to deal with issues relating to entitlement.

> *We would see the patients, we would advise the patients and we will treat the patients and we are separate from whether the patients are eligible for treatment that they receive or not.*
>
> **D3male**

Protection and building trust

On occasion, the desire to protect and defend African people, led the professionals who worked with them to be overprotective and this tendency was acknowledged by some of the informants. One social worker recognised that, when it came to confidentiality issues, other departments sometimes saw them as being 'very precious'. She saw this charge as arising from a need to protect against the consequences of inadequate understanding of the importance of confidentiality for HIV-infected African people.

> *I think we're a bit overprotective, but that could be... because of lack of awareness with other agencies. So like this list is referring and putting status, they're not fully aware around confidentiality, whereas we would be; then you are a bit overprotective.* **S1female**

Another informant referred to being '*too precious*' and overly '*sensitive*', allowing that this response could actually be counter productive; being overprotective could even compromise the ability to run effective testing campaigns:

> *I wouldn't want to see campaigns not happening or not being successful because we were being too precious.* **V2female**

A key concern for professionals working with African people was the ability to build trust, and this appeared to be closely related to the supportive and sometimes protective relationship that they had with their clients. There was a strong sense amongst those with first hand involvement with Africans that their

motivation was 'the best interests' of the African person. Yet they generally recognised that, for the patient, there was often a degree of insecurity in the relationship to begin with, and to achieve the necessary trust the relationship needed to be nurtured and protected.

> *So I think there's been a couple of times where people haven't given us contact numbers, or may have given us incorrect names or addresses, until they've reached a point where they know that we are confidential and we're acting for their best interest.*
>
> **H3male**

4.3.3. Challenges in relationship: understanding the African perspective

Discussions around the perceived impact of African culture and beliefs upon the uptake of voluntary HIV testing were prominent within the interviews with professionals. There were substantial attempts to understand the perspective of African people, including their knowledge of the disease, past experience of HIV in Africa and the multiple challenges faced by many. Although some participants referred to diversity, recognising that the *'African perspective'* is not homogenous, there was a strong sense within the interview data that a continent-wide identity was being applied to African people.

Chapter 5 will explore the perspectives of African people more fully, based on data from the interviews with African participants. The focus of the current section is on the professionals' attempts to understand the worldview of African people, and the frustrations and difficulties that arose in their relationships as a result.

Understanding culture and beliefs

It was widely acknowledged by professionals that the uptake of HIV testing, and access to health and social care more widely, is influenced by the health beliefs that African people may hold, and that these may be very different to Western health constructs. Some professionals specifically associated delay in accessing HIV testing by African people to a 'laid back' approach to health, in which there

is little anticipation of the future, especially if it might mean confronting potential difficulties.

> *I think that some people have different models of disease to the Western idea and I think that they don't necessarily share the West's view of knowing whether they've got an illness and knowing what the future holds. And they're more keen on just being where they're at and then something happens and they deal with it when it happens rather than in an anticipatory way.*
>
> **D3male**

Professionals felt that religious belief played a significant role in the health seeking behaviour of African people and attempted to understand the potential influence of various beliefs upon testing, treatment and care. Many informants made connections between aspects of religious beliefs and delay in HIV testing, asserting that it was not uncommon to encounter African people who believed they had a supernatural protection against illness. One doctor, reflecting on the reasons why partners of women known to be infected with HIV persistently 'refused' to be tested, fairly typically included a religious dimension in her explanation.

> *The comments that we've had have been, "It can't be true, we can't have HIV, God will take care of us." There's a very strong religious belief that God will cure or God will protect and therefore they can't be ill.* **D1female**

Conversely, a rather fatalistic approach, also directly associated with strongly held religious beliefs, was seen to be a factor in the way Africans regarded potential HIV illness. Informants postulated that some African people hold a belief that they will be under God's protection up to the point when it is their time to die. As this is beyond their control there is therefore no benefit in taking any action to attempt to alter the course of events.

> *There's very, very strong religious overtones and fatality about it. Almost as though God will protect them until they get really, really sick and if they're going to die, they're going to die.*
>
> **D1female**

Discourse on various aspects of African culture was prominent across the range of interviews. As with beliefs there was a tendency for culture to be considered as a single cross-continent entity, rather than fully to explore diversity within it. Although some informants were aware of inter-country differences, they acknowledged that in their day-to-day practice differentiation was rarely made.

> *We are, I think, somewhat naïve in our interpretation. We tend to lump them all in the same category, which is not necessarily accurate.* **D3male**

Culturally determined gender roles and behaviour were felt by professionals to have an important bearing in relation to HIV. For example, they felt that undertaking an HIV test might be impossible for some African women without first gaining permission from her male partner, and that the cultural imperative of childbirth might mean risking transmission of HIV in sero-discordant relationships.

> *In general, in African relationships there are some practices and norms that you would not necessarily find in maybe UK white relationships, e.g. child bearing and you know issues of gender, power, and things like that.* **V1female**

Whilst most informants thought it was culturally difficult for African people to discuss sex and diseases like HIV that have a largely sexual origin, many professionals felt that it was particularly difficult for African men.

> *I think culturally the gender difference is quite obvious sometimes, in as much as the women appear to be more comfortable talking about sexual questions.* **H3male**

Some professionals acknowledged the impact of African people's reticence in discussing sex upon themselves, their practice and their relationships with African people. These professional participants were well versed in discussing such issues in general, it being part of their normal work, yet they sometimes found discussions with African people about safer sex became *'incredibly fraught'* [V2female].

> *I always find it much harder talking about sexual health and*

> *giving sexual health advice with African people, because in my experience it has been much harder to engage them in talking about their own sexual health and their own sexual practice.*
>
> **H2male**

There was widespread recognition by professionals of substantial difference in cultural heritage between themselves and African people. Further, some African cultural norms were felt to have a significant impact upon HIV prevention, treatment and care. However, professionals acknowledged their difficulty in defining these cultural differences and understanding their context and framework because they were from a largely white middle-class social background.

> *I'm a middle class white woman and how can I begin to even understand African cultural norms?* **D1female**

Most clinicians recognised the limitations that cultural differences imposed on their consultations with their African patients, and pointed particularly to issues around building trust and being able to elicit sensitive information.

> *With UK patients I feel that I have more of an idea why some of them are not revealing information. And that maybe culture, it might be that my cultural experiences don't extend to theirs and therefore I'm not able to entirely relate to theirs.* **D3male**

Not only did professionals recognise a 'cultural gap' in their understanding of the perspectives of African people, they were also aware of the effect of difference in ethnic and social background between themselves and their African patients. Thus, even where professionals had some understanding of African cultural practices it was felt that ethnic difference was a barrier to building a relationship of trust.

> *I've never had anyone volunteer the kind of sexual practices that I'm aware of...all of the stuff about douching and dry sex and female genital mutilation. Nobody has actually said anything to me here at this clinic about that... nobody would trust a white doctor I'm sure (laughs).* **D1female**

However, it was also felt that difference in ethnicity could be advantageous. Recognising that HIV is heavily stigmatised in African communities, professionals felt that some African people felt more secure engaging with HIV services that were remote from their own community.

The challenges that cultural issues posed for professionals led some to call for appropriate training to better understand African culture, and to assist them in overcoming perceived cultural barriers. One consultant felt that it might not be possible or even necessary for all health professionals to be trained to the same degree and proposed that in each health care setting there should be at least one person who would have specialist knowledge.

Conflicts and compromise with the Western biomedical model

In close relation to discourses around culture and beliefs, many professionals reflected upon the challenges of adopting a Western biomedical model of healthcare with African people. Some participants felt that African people held '*different models of illness*' [D3male] and that poor understanding of these by healthcare professionals could limit the provision of clinical care. It was claimed by one consultant, for example, that inflexibly adopting a '*Western approach*' could be detrimental to the relationship between clinician and African patient and could serve to undermine trust.

> *So how do you discuss things in their terms as opposed to leap into: "Well you've got these antiretroviral things". "What is antiretroviral?" "Well, it's a retrovirus." "And what...?""Well, actually, this is a virus which actually can't replicate by itself, but replicates in the cell" ... and they might be going away thinking: "This is a typical Western approach to things" There'd be whole levels of anxiety going on. "They are only trying to confuse me." "This is another propaganda [attempt]"* **D2male**

However, even when they recognised that the Western biomedical model had limitations as a model of illness within which to place African patients, professionals generally held it in high esteem. On the whole the response to a perceived mismatch in models of illness was an attempt to educate patients into following medical advice and encouraging them to follow health care protocols

including regular follow up and medical monitoring. For example, in discussions around medication compliance clinicians felt they had a measure of success in 'Westernising' the approach of the African patients with whom they were engaged over a period of time. This often involved compromise, with one clinician referring to patients *'meeting us halfway in accepting Western ways'* [D1female].

Professional status

The relationship between African and professional was influenced by the status of the professionals, who perceived it to be marked by deference and respect. This affected the relationship in different ways, according not only to the confidence and background of the African person, but also according to the role of the professional. One consultant, for example, reflected upon his sense that there were inherent difficulties for him in talking to African patients, and sometimes he sensed that patients would agree with him regardless of whether they understood what he said.

> *I get the feeling as a consultant in the clinic one tends to have a slightly deferential treatment by the patient and therefore they would say "yes" to you, even though they may not follow what [you're saying].* **D3male**

Generally, informants felt that African patients had a great deal of respect for, and confidence in, health professionals, with respect for general practitioners being particularly noted. However, there was a perception that some African people view professionals as authority figures who are *'part of the system'* [V2female] and may be reluctant to access services because of uncertainty regarding where health professionals *'lie in the whole system of asylum seeking'* [H3male] (See Power and powerlessness on page 137).

Communication

Being able to establish good communication was considered a core element of relationship building and was discussed in most interviews. Generally

consultations were conducted in English, the use of interpreters being infrequently necessary. When they were used, communication was especially difficult and a number of informants expressed concern about the impact upon the dynamics and content of the consultation. On occasion, it seemed preferable to struggle without an interpreter rather than introduce a third person into the relationship.

> *I think we always worry that if you're asking for an interpreter it's difficult because you've then got someone else in the room and people may not feel that they are able to be as open to you as they might otherwise have been. And particularly I suppose ... in this area of work because you don't know what kind of judgments and personal issues they're going to bring into the room so that's quite difficult.* **H1female**

One of the barriers to good communication and subsequently to building good relationships with African people was an element of dishonesty within the relationship, noted by some, although not all, of the informants.

> *There's times when people aren't that honest, or a bit evasive about their refugee status, or asylum seeker status.* **H3male**

Although this was understood partly in terms of issues around immigration status, it was also noted in relation to two examples of African men initially denying they were homosexual, and in relation to the use of condoms.

> *I do get the impression at times that people aren't using condoms at all. They'll say that they are, but you feel that they probably aren't.* **H2male**

Most participants stressed how the quality of communication could impact upon clinical outcomes and recognised the challenge this presented. The way in which information is presented was seen to be an important determinant of whether or not a person will undertake an HIV test. For example, one consultant felt that it was counterproductive for doctors to attempt to convey complex information without recognising the levels of understanding that their African patients may have. Generally there were strong calls for discussion and counselling to be non-

judgmental and for risks to be presented in a dispassionate, factual and accessible way.

> *It's easier then to say to them: "These are actually the facts". So it's not about discriminating, it's about saying to them: "It's for your benefit that we're advising you to have a HIV test".*
>
> **H3male**

Experience and understanding of HIV

Professionals frequently made links between the knowledge and behaviour of African people in the UK regarding HIV, and the extent and nature of HIV disease in Africa. Informants attempted to make sense of what they perceived to be the 'African perspective' by referring to factual information such as the prevalence of disease and inadequate treatment availability in Africa, as well as drawing upon the stories that had been presented to them by their patients. Thus professionals were keenly aware that for many African people, HIV was strongly associated with death.

> *A lot of people that I have worked with in the past have sort of been exposed to that environment where diagnosis of HIV means death.* **V1female**

It was widely recognised that the experience of HIV for African people was often intensely personal, with many having witnessed the death of close family members *'so the experience of HIV is very raw'* [V2female]. Professionals on the whole recognised the significance of this in attempting to understand the perspective of the African person, acknowledging that painful past experience might profoundly influence fear around the possibility of having the same illness.

> *They may have seen several members of the family die, friends, people from the village or from around where they live. They have seen a lot of people die and really nasty circumstances. So there will be big fear there as, "What if that happens to me? The same thing is gonna happen." Because there isn't always an understanding that there are treatments available.* **H2male**

There was a widely held belief amongst professionals that fear of HIV was an important barrier to the uptake of HIV testing. Further, participants commonly understood this 'African perspective' to arise from a belief in the inevitability of death; a belief that had been forged in a setting where, for the most part, treatment was unavailable. Clinicians believed that there was a need to overcome this perceived ignorance of treatments and to raise awareness of their availability in the UK, thereby ameliorating some of the perceived reluctance of African people to come forward for testing.

> *In some of their own countries there is no treatment available and therefore why know that you've got something waiting for you when you can do nothing about it... I think African patients maybe need to know that drugs can help them and they may need to know the benefits of those drugs.* **D3male**

Stigma

The concept of stigma was raised across the range of interviews, with professionals commenting that the extent of HIV related stigma within African communities was substantially greater than that found in the indigenous white population.

> *HIV is obviously more prevalent amongst African communities, the stigma seems to be much, much greater as well, having HIV, and we have found some people ... who have been very scared about their own community finding out about the HIV.*
> **H2male**

Professionals identified the fear of stigma as a specific barrier to the uptake of HIV testing, making it especially difficult for an African person proactively to seek HIV testing. They related this to their perception of the situation in Africa where HIV is closely linked to 'promiscuous' sexual behaviour.

In their relationships with African people many professionals attempted to counteract the perceived association between multiple sexual partnerships and HIV by making deliberate efforts to reassure African people that they, as health professionals, were not implying that being infected with HIV reflected previous

'promiscuous' behaviour. Indeed, many clinicians believed that being able to convey this to their patients was an important first step in building the clinical relationship.

Perception of risk

Professionals commonly found a substantial mismatch between their own assessment of an individual patient's risk of infection and the patient's self assessment of risk, with many African people who were in fact infected with HIV simply not realising they might have been at risk of acquiring the disease. Sometimes, even when a health professional had attempted to prepare a patient for the possibility of a positive HIV test result based on an objective assessment of risk, the diagnosis still came as a great shock. This was the case on a number of occasions for HIV infected African patients diagnosed through the antenatal screening programme. Clinicians felt that the self-perception of risk in these cases made it unlikely that such people would proactively seek HIV testing based on an assessment of their own risk. Generally professionals interpreted the stark contrast between the known high prevalence of HIV in many African countries and the perception of personal, individual risk by African people as a form of denial.

> *Sometimes you feel it is a very 'head buried in the sand' kind of view that they're a bit concerned but they don't really want to relate it directly to themselves as an individual.* **H1female**

Participants felt that individual African people associated their likelihood of being infected with the development of symptoms and there was widespread agreement amongst professionals that many African people found it hard to believe that they could be infected if they did not have any symptoms of disease.

> *... they can't believe they've got it themselves because they're well.* **D1female**

On the whole, there was strong agreement across the range of interviews that the development of symptoms arising from HIV infection was the most likely determinant of the decision to seek HIV testing proactively. Therefore, to

encourage the uptake of HIV testing, professionals felt it was necessary for it to be more widely used as a screening tool.

The position of HIV in the hierarchy of needs

For most participants, an important aspect of understanding African people's perspectives of HIV testing was to acknowledge that many Africans living in the UK face a range of social, psychological and economic hardships that are often a higher priority than their health needs. Informants who had experience of working directly with individual African people often presented a holistic view, seeking to set out the wider picture of the struggles and problems encountered by some African people living in the UK. A recurring theme was that HIV infection can not be seen in isolation; that to provide appropriate access to testing and care requires understanding of the worldview of those who carry, or might carry the infection.

Thus, some key informants recognised that HIV might be only one part of a complex picture of needs. For example some African women infected with HIV may have been forced to flee their country of origin having suffered violence and multiple rapes; the psychological trauma of their experiences might be more prominent in their mind than the thought of possible infection with HIV. In such circumstances informants understood that proactively seeking HIV testing might well not be a priority, and even when a diagnosis is made the ongoing care must recognise that HIV infection is only one part of a much bigger picture.

> *There's so much other stuff going on for them that HIV isn't really a big issue in the big scheme of things.* **H3male**

Professionals commonly discussed the practical issues faced by many African people living in the UK. Overwhelmingly, there was considerable sympathy for the plight of African people struggling to find suitable accommodation and employment, and attempts to understand the HIV testing process from the perspective of the African person in the light of these difficulties. These practical issues were often seen as a major influence on how, when, and even whether

African people access health care in general and HIV testing services and subsequent care in particular.

> *There are issues regarding their immigration status, their working relations or housing and different sorts of social issues that are not really HIV specific. So those issues really determine how a person would access, not just HIV testing but health services in general. So a lot of them have other priorities in their lives.* **V1female**

The complexity of these competing priorities was conceptualised by some informants as a 'hierarchy of needs' with recognition that the professional's judgement of the place of HIV within this hierarchy may often be different to that of the patient. Some participants were explicit that it was important to work, as far as possible, with the priorities held by patients.

Frustration

While professionals were generally extremely supportive of and positive in their attitudes to African people, perceived difficulties in the relationship led some to feel frustration when seeking to overcome some of the underlying barriers.

> *...their sexual health is not the main priority in their lives.... so we are getting quite frustrated because we have got somebody who may have HIV and they're not doing anything about it.* **H1female**

There was particular frustration around the testing of male partners of African women diagnosed with HIV infection. This was referred to as an ongoing problem by clinicians who, despite their best attempts, could sometimes not persuade individuals to be tested. Some clinicians went further, on occasion using stronger expressions of frustration. For example, in discussions around the use of condoms, the mismatch between the agenda of the clinician and the actions of the African patient was described in terms of a battle.

> *The men don't usually like using condoms, and that is an ongoing battle. We give condoms away. We try to give the women condoms and we try to empower the women to negotiate the use of the condom; it's an ongoing battle.* **D1female**

Despite frustration and a sense of battling with patients, professionals felt they were acting in the best interests of their patients. Whilst some professionals recognised the potential for this to be seen as paternalistic and controlling, they preferred to speak in terms of giving choice, seeking to impart their knowledge to enable patients to make informed decisions.

> *I don't mean I want to control them. I mean I want to impart on them the benefit of my wisdom so they can make an informed choice.* **D3male**

4.4. Recognising self: personal feelings, professional dilemmas and political positioning

While professionals demonstrated substantial attempts to understand the African perspective, they did not entirely externalise the process of HIV testing and care, recognising their own influence on the decisions and actions involved. Acknowledgement of the role they and other professionals played, and their associated feelings, recurred across the range of interviews. Personal beliefs and political positions were often explicitly expressed although the degree to which an individual chose to reveal their own perceived areas of vulnerability in these public accounts varied considerably; whilst some expressed clearly the difficulties they experienced in providing HIV care for African people, for others it was implicit in their accounts.

4.4.1. Professional competence and confidence: acknowledging uncertainty in managing HIV

Professionals frequently reflected upon their practice and the practice of others, presenting some issues as dilemmas or uncertainties, and on occasion expressing their discomfort within the professional role. Most clinicians emphasized the importance of knowledge and competence in the process of HIV counselling and testing. Competence and confidence are closely linked; professionals become anxious about managing HIV when they feel it is beyond their level of skills,

knowledge or experience. Thus one consultant, acknowledging that medical practice is not static but subject to regular change, used the example of obtaining informed consent to illustrate the anxiety felt by health professionals, including himself, about keeping up to date with best practice.

> *There's real anxiety what informed consent is. I think most medical practitioners know that everything moves on every one or two years. And if you're only doing a small number, are you sure you are getting the right informed consent?* **D2male**

The concept of professional anxiety was recurrent and although many participants recognised that they were *'sitting in a very privileged position'* [D3male] in terms of their own knowledge and experience, there remained aspects of HIV care which they continued to find challenging. There was a strong sense of their own inadequacy in being able to communicate across perceived cultural boundaries and a feeling of sometimes being unable to achieve the best possible clinical outcomes as a result. Thus, professionals often struggled to discuss sexual practice and to raise certain relevant subjects within the consultation.

Having a good knowledge of their subject was seen by participants as the key to building confidence and therefore training was considered crucial in overcoming anxieties associated with providing appropriate care.

> *I do wonder whether people are more scared of counselling people for HIV testing than they need be... I know what I would say counselling someone, because I know the risks and benefits of testing... maybe there's an educational need there.* **D3male**

Commonly, specialist HIV clinicians felt that the reluctance of other health professionals to engage in HIV testing activity was related to fear arising from lack of knowledge. This fear could present itself in the form of very strong objections to offering the test at all, but these objections could be overcome by giving appropriate training and supplying knowledge.

> *We did have some midwives that felt very strongly that we shouldn't be offering the tests but I think that was more to do with fear about how to offer the test.* **M1female**

Most participants had at least some experience of being involved in cases where clinical management had been sub-optimal. It was generally accepted that, at least occasionally, mistakes are inevitable. The story was told of a mortgage application being turned down following the release of HIV testing information, even though the person involved was known to be HIV negative. This anecdotal account served as an example for one informant of how 'something going wrong' can undermine the professionals' confidence within subsequent consultations.

> *It does have a knock-on effect because then people remember stories like that and think, "Oh gosh, I can't say to this woman it's going to be okay."* **M1female**

The broad acknowledgement that errors occasionally occur added to the sense of unease sometimes felt by professionals within a consultation. Thus, even in cases where the clinician is well aware of 'best practice', when asked for reassurance on an issue that might lie partly outside of their own jurisdiction, they may feel uncomfortable.

> *... there are sort of anecdotal breaches and that is why I always feel extremely uncomfortable about blanketly reassuring, regardless, it's a difficult thing to do because you'll always come across somebody who's had a problem.* **D1female**

4.4.2. Beyond the professional: personal feelings and political positioning

Across the range of interviews there was extensive discourse on issues extending beyond the more pragmatic considerations of HIV testing and care for Africans living in the UK. It has already been noted that professionals were sometimes drawn into the personal drama of their patients, and on occasion this was expressed with both empathy and compassion, going further than merely a distant professional-client relationship (see section 4.3.1). It was perhaps engagement at this deeply human level that gave rise to some of the more strongly held convictions, both personal and political, which were offered by some professionals during the interviews.

The fear of the charge of racism

In response to questions focusing specifically on possible approaches to increasing the uptake of HIV testing in African communities through targeted HIV testing, participants expressed a range of views, some of which were highly emotional and personal. There was extensive discourse around the way in this might be seen as racist, with most key informants raising the issue spontaneously and discussing it at some length. The professionals often acknowledged their own discomfort at the possibility of being seen as racist, even when the policy itself might arise from higher motives.

> *When we've talked about this sort of thing the immediate response has been they [African people] may see that as being stigmatising, as actually being racist, which I think is a very, very difficult thing to deal with because actually it would be done with the best of intentions.* **P1female**

Many professionals expressed their preference to 'universalise' the offer of a test, thus avoiding the potential of being seen as stigmatising or being racist.

> *On a personal level, I would prefer to just offer it to everybody. Not to offer it to people that are coming just from Africa or some of the high risk areas.* **M1female**

Recent changes in practice in the genitourinary medicine clinic had made it easier for health care workers in this setting to offer the HIV test to all who accessed general sexual health services, allowing it to be seen both as universal and routine. Similarly, a number of professionals felt that the offer of antenatal HIV testing to all pregnant women, regardless of an assessment of individual risk factors, made the process easier.

> *If you're targeting at specific groups then you could be seen as very racist, very homophobic or whatever and that was the whole argument behind introducing the offer of antenatal testing universally, even though we're picking up a large number of African women.* **D1female**

A universal approach was preferable to professionals concerned about accusations of racism that might arise from testing targeted to a particular group

based on country of origin. However, the need to extend voluntary HIV testing further into the African community was recognised. It was generally agreed that there were resource issues surrounding more broadly offered universal testing and without some targeting there would be many tests for a very small yield of HIV diagnoses. Therefore, although it was seen as challenging, a need for targeted testing was acknowledged by some participants.

> *I think that you could have selected testing. I think it's difficult to deliver that in an equitable way, which is not seen as being racist. I think that's a challenge.* **D3male**

The response of African people to targeted HIV testing was an important consideration for professionals, many of whom expressed a strong abhorrence of racism. Participants were especially concerned to ensure that they did not open themselves to the charge of racism, and there was a widely held feeling that any move towards targeted voluntary testing must be done with great caution.

> *Very definitely it could be picked up as discriminatory and I think it would need to be done very, very carefully.* **H2male**

The way in which HIV testing is offered was considered a key factor in whether targeted testing would be an acceptable approach. It was felt that the words used should be chosen with care, with emphasis being placed both upon the potential benefits to the individual of knowing their HIV status, and upon ensuring that the patient understands that there is choice.

> *I think it's acceptable, I think it depends on the way that it's done.... I suppose it depends on the way it is worded as well... I think it's fair enough for it to be asked and then see what the patient feels after that.* **H3male**

Some informants maintained that HIV testing should not be targeted purely on the basis of ethnicity. One informant was particularly vehement in her response when she was asked whether it might be acceptable to offer an HIV test specifically to an African person.

> *NO! Because if a white woman came in and she'd come in for something, she could have been to Africa on holiday, but you*

wouldn't say it to her. **S1female**

Further discourse around this subject led this and other informants to clarify what they felt to be a more acceptable basis on which to offer an HIV test. This focused more on previous place of residence than on ethnicity. Some informants felt that emphasizing the country of previous residence would overcome the potential charge of discrimination, even though it was implicitly accepted that a person's ethnicity would be a significant factor in this.

> *You would have to make sure that your criterion for selecting people is not necessarily based on race. .. So you would have to perhaps say anybody who lived in Africa should be tested rather than on race, because I think otherwise it becomes perhaps an issue that maybe perceived... as racism.* **D3male**

Some professionals recognised that however sensitively the offer is made there is always likely to be some criticism. One informant based her view on reports from African women who were offered testing during pregnancy, prior to the introduction of universal antenatal HIV testing. She claimed that however carefully the offer is made there might always be some who feel a level of discomfort about being offered an HIV test, but that the fear of racism should not deter health professionals from giving clear messages about HIV.

> *I have spoken to a number of African women who have said, "They only asked me to have an HIV test because I am an African and that's racist"... I am sure the message was put across as, "You come from a high-risk country, this is a way of us being able to protect your baby, and so on," there is still that sense that there is an element of racism in there and I think in some ways we can be too sensitive about that and not be giving clear messages to people because we are worried about racism.* **V2female**

Choice and compulsion

Professionals felt very strongly that targeted HIV testing could only ever be acceptable if it were *offered,* with emphasis that the patient must always remain able to choose whether or not to accept. Provided patient choice was maintained, participants felt there were potential benefits associated with the test being

proactively offered by health professionals. It was seen as an opportunity to provide information and to raise awareness, as well as providing easy access to HIV testing.

A number of informants raised, with concern, the possibility of compulsory testing and were particularly critical of any suggestion of testing immigrants at the port of entry as had been recently reported in the media.

> *I am totally in favour of people having access to the kind of information and support that would enable them to make an informed choice about having a test... I am very wary about any kinds of campaigns that are about forcing people to be tested.*
>
> **V2female**

A single contrary view on compulsion was expressed by one informant. On the issue of targeted testing she spoke from a public health perspective, rather than focusing on the needs of individual African people. Interestingly, she expressed her own discomfort in holding a 'right-wing' professional perspective which she felt was not her natural political position.

> *If I was having a public health hat on I would probably be saying that I've become glaringly right wing about testing on entry and establishing status and I'm appalled that I've reached that view ... and it weighs into all the debates around refugees and asylum seekers and access to care and I find all my left wing marching friends are of very similar if not even righter views about it and I find it really quite difficult.* **P2female**

Political positioning

The political dimension to HIV testing, especially as it relates to African people in the UK, was raised by a number of participants. Many informants went beyond their clinical or social care remit, expressing a political stance on certain issues that they wished to raise. Professionals believed there were certain aspects of HIV care that required political will at a national level and were aware of competing agendas both in terms of resources and politics. Generally, they understood the complexities and sensitivities around the provision of HIV care

and for the most part accepted the political difficulties that were associated with bringing messages around HIV and African people into the public arena

> *I think actually this Government hasn't too bad a record on HIV but I think that they feel hidebound in terms of how to manage the message because what we are seeing at the moment is if anything, a greater stigmatisation of HIV given that the majority of new diagnoses are people fairly recently arrived in this country from Black African countries.* **V2female**

Thus, attempting to ensure that African people who may be infected with HIV were given due care was understood to conflict with the political response to perceived hostility arising from increasing immigration. Professionals generally recognised that questions around immigration and access to free NHS treatment for example did need to raised and be given careful consideration at a national political level, and they called for clear and consistent political decisions to be made.

> *I think it's a problem for the country as a whole... but I think that the solutions are political.* **D3male**

A number of informants criticised the media and the way in which it was perceived to present a biased and sometimes inflammatory view. Professionals complained that the prevalence of HIV in African people in the UK had been presented in an alarmist way and unfairly related to 'health tourism', and some were concerned that this was a potential barrier to the introduction of targeted testing.

> *What I am worried about is the Evening Post headlines and the kind of backlash that there is in the community as a whole around refugees. There is already tensions around that and to actually say people from Africa, sub-Saharan Africa are potentially a source of infection, I think you just need to be very careful about it.* **P2female**

The political issues raised by informants were wide ranging and disparate; some criticised government policy on dispersal of asylum seekers, whilst others raised entitlement to NHS care for example. The extent to which professionals engaged

with issues at a political level is notable, as is the degree to which they acknowledged their personal views within their accounts.

4.5. Setting the agenda: power, priorities and structures

Throughout the interviews it emerged that decisions around testing often involved many layers of influence; multiple agendas were often present, even if not all were fully recognised by all players at any particular point in time. Thus, for example, agendas set at a national level impact local implementation plans; the priorities set by the Primary Care Trust profoundly affect the capacity and extent of HIV services; and the interests of individual health care professionals influence how proactive they might be in engaging with HIV testing. Further, issues of power within relationships and within society were held to affect the response to HIV testing, with fear around immigration issues being presented as a particular barrier to accessing health care in general and HIV testing in particular. Structures, it appears, may not be in place to meet the agendas of African people but rather be based upon the needs of the indigenous population and those who know the workings of the NHS.

4.5.1. Whose agenda is it: recognising status and powerlessness

Whose agenda is it?

Participants stressed the importance of being 'patient-centred' in recognising the complex needs of an individual African patient and tailoring the offer of HIV testing accordingly. They claimed that patients are more likely to undertake HIV testing if they understand the potential advantages to them as individuals. However, some interviewees claimed that being patient-centred was not always central to HIV testing. The antenatal screening programme, for example, set a target for tests taken, thereby encouraging health professionals to adopt an agenda which may not match the wishes and needs of the individual patient.

> *Instead of saying that we should recommend it, they were saying that we should not only recommend it but we should get 90%*

uptake. So it was really telling us we should be doing it.

M1female

There was some concern that a target-driven approach may be counter productive and possibly resented by African people. One consultant was particularly keen that African people might trust health professionals, believing that they work in the patient's best interest rather than attempting to meet the targets that have been set for them.

> *... [so that] it's not just seen as, we want to get your HIV testing done - that is our objective we want to have an HIV test on 30% of your population.* **D2male**

In some interviews it was noted that clinicians sometimes have an agenda that arises from their own personal interests. For example, it was suggested that the attending clinician, prior to some surgical procedures, drove forward the HIV testing process because it was in the surgeon's interest to know whether the patient was infected with HIV.

Power and powerlessness

The perceived imbalance of power in the doctor-patient relationship was seen by some as a particular danger in offering an HIV test opportunistically to an African patient, especially when the patient comes from a culture in which the doctor is seen as an authority figure who is treated with a great deal of respect. Some informants suggested that particular care is needed to ensure that the patient is aware that they have a genuine choice, and that future care would not be affected by a decision not to accept the offer of an HIV test.

In the view of professionals, a substantial factor in the vulnerability and powerlessness experienced by many African patients related to their uncertain or tenuous immigration status. Whilst some were thought to have entered the country illegally, others had entered on a student visa and had become illegal immigrants by outstaying their visa. A substantial number of African people were in the process of applying for asylum, and it was felt that such people were

reluctant to come forward for HIV testing in the belief that they might have their application turned down if they were found to be HIV positive.

> *The worries about those applications being influenced by their HIV status might be one of the reasons why they don't actually access treatment.* **V1female**

Engaging with statutory services was felt to be problematic for those whose immigration status was not secure, and informants working in the voluntary sector suggested that some African people felt more comfortable accessing their services.

> *They'd much rather come here and see if we can give them a test than go to the clinic ... I've got some people who haven't even got a GP because they don't want to get locked into the system for fear of being found out as it were.* **V2female**

Issues around access to free NHS treatment were raised in some interviews, with participants suggesting that the government was 'clamping down'. Some professionals felt that the application of stricter entitlement regulations was beginning to have a detrimental impact upon uptake of HIV testing.

> *An increasing barrier is it's becoming more known that if you're here either illegally or on certain types of visas, that you're not gonna be entitled to free care.* **H2male**

There was a common feeling across the range of interviews that African people face discrimination and oppression, being amongst the weakest groups in society. Even other groups, who might traditionally have been seen as oppressed, were in a more powerful position than African people, and some professionals were concerned that racism and hostility might be set to increase further.

> *Already I sense in the HIV movement there is a backlash ... particularly gay men who are feeling that resources are being diverted to another group and they are unhappy about it ... the oppressed oppress the more oppressed.* **P2female**

4.5.2. Conflicting agendas: priorities and political will

National and local priorities

Professionals felt that HIV had become less of a priority at a national level over the previous five years and some felt that there was a need for a government-sponsored HIV awareness campaign. Several professionals referred to the ending of 'ring-fencing' around resources intended for use with HIV related services, and strongly criticised this move. Most participants recognised that there were difficult decisions to be made in prioritising the use of limited financial resources. Unsurprisingly, those working for the Primary Care Trust (PCT) took a broader view of health care needs, seeing a wider picture than those whose work was more closely linked with HIV care in particular. Thus, the health promotion specialist believed that it was for the PCT to set its own priorities, but felt further information was needed for this to be done. The extent of undiagnosed HIV in the African community and the potential public health risk associated with spread of disease were seen as important determinants in setting the level of priority for work with HIV in African communities. However, the lack of available information relating to these aspects could undermine attempts to give appropriate priority to work that would benefit African communities.

Participants recognised that the broad agenda of statutory agencies necessarily had a massive impact on HIV testing services and the resources allocated to improving the uptake of testing by African people. Thus, even if the public health imperative for more HIV-related work with African communities were recognised, the PCT's agenda may not allow for it to be done.

> *If you're looking at it from a pure public health perspective you would say we'd want to identify as many people as we possibly can to make sure they get into treatment early and stop the progression, or if you're looking from a financial point of view you would say the caseloads are completely full at the moment... we're not going to do that much to promote it.* **P2female**

Financial resources

Conflicting agendas at the national and local level are often played out in competition for limited financial resources. Funding for HIV care was seen to be under threat from many other health care demands.

> *It's a very tiny fish in a massive pond and it's competing with so many other health demands at the moment that I think that the likelihood of it getting squeezed out is still very great.* **V2female**

The setting of agendas and priorities at national and local level cannot be divorced from the provision of appropriate financial resources to enable implementation. Many professionals expressed frustration that local initiatives, for example the introduction of antenatal HIV testing, were not properly resourced. Several clinicians were critical of the 'purchasers' who they felt did not provide an appropriate level of funding for local HIV services. The criticism levelled by one consultant was particularly robust. Throughout the interview he criticised management with comments such as *'there's no joined up thinking'* and that a *'disjointed'* approach to service provision with no single person in a position to advocate *'suits the purchasers because they are interested in next year's budget'* [D2male].

However, it was clear that there were enormous pressures on local funding and purchasers were sometimes faced with difficult dilemmas.

> *Well are you asking me morally or do you ask me as a Commissioner whose got a 1.7 million pound overspend in their budget who's actually going to be saying actually I don't want you to find me anymore people thank you very much I've already got enough and we need to talk about how we manage the existing caseload.* **P2female**

4.5.3. Accessing health care: structural barriers

In response to a general question addressing access to HIV testing, participants generally felt that the main site for initial access into HIV services was the genitourinary medicine clinic, although it was also known that HIV testing was

available through primary care. All participants were aware of the introduction of universal antenatal HIV screening, with some also referring to HIV testing carried out in hospital patients when appropriate. Although patients occasionally sought testing at the Terrence Higgins Trust or at the HIV outpatient clinic it was not available at these sites except in the latter case for the partners of HIV-infected patients.

Many highlighted the unusual structure of HIV services in the Bristol area. Testing and care services are in geographically distinct locations, operated by different Trusts, and separately staffed. It was felt that this arrangement had both advantages and disadvantages, and these views varied depending upon the setting in which the informant worked.

In discourses focusing on the structure and organisation of services, many professionals felt that there may be limited awareness amongst some African people about how to access health services in general, not only in relation to HIV.

> *... not understanding the health service and how those tests can be accessed, so maybe knowledge and the basic social systems.*
> **P1female**

Accessing sexual health services was seen to be even more problematic. Some of the issues raised related to the perceived stigma around attending a genitourinary medicine clinic, and the likelihood of accessing services was seen to be dependent upon self-confidence as well as knowledge. It was also commonly recognised that resource issues made gaining access to the clinic particularly challenging. The service was seen to be under pressure, often it was difficult to arrange an appointment and even getting through on the telephone could be difficult.

> *So I think people go to the GU and see it as a place that you go to if you've been a bad boy or girl and you've got to sort yourself out. And I'd really, really like to get away from that image... In Bristol we've got to work with what we've got, our old buildings and an under-resourced service.* **P1female**

A number of professionals felt that some African people did not access HIV testing services because they were unclear about their entitlement to treatment. There was felt to be further confusion surrounding access to the genitourinary medicine clinic, even though HIV testing is available free of charge to all, regardless of immigration status.

> *I think issues around whether if they were positive would they need to pay for treatment or do they need to pay for the tests? People have been unsure about whether they can attend here.*
>
> **H3male**

It was commonly felt that there was potential to overcome at least some of the structural barriers to HIV testing by extending its availability within primary care, and this will be discussed in the next section.

4.6. Responding to increased need: broadening provision, the role of primary care and the way ahead

Professionals across the range of interviews reflected upon the increasing number of African people living in the area, the increasing number of African people being diagnosed with HIV infection, and the late stage of disease at which diagnosis was often made. A number of barriers to voluntary HIV testing were identified and strategies suggested, some of which have been discussed in previous sections of this chapter. This section will draw together discourses around broadening the provision of HIV testing through greater involvement of non-specialist providers, particularly focusing on primary care.

4.6.1. Cooperation, support and collegiality

Participants generally stressed the importance of good relationships between professionals working in HIV-related services. The professionals taking part in the current research were part of a fairly small group working in the same area, with many of them knowing each other. Many of the interviewees had worked with other professionals in HIV related projects or work and there was warmth of feeling across the different professional groups. For example, several had

collaborated in setting up the recently established antenatal testing service, and some spoke of other professionals from the vantage point of having worked together in this project. The experience of working together and across disciplines had been positive, and the training and support provided was appreciated.

> *... but if it was something more complex and you felt this woman actually needed further help and advice, then you could refer them to the GU Clinic... and I think that put midwives minds at ease*
> **M1female**

The majority of respondents recognised the need to expand the availability of HIV testing services and that for this to be possible it would be necessary to engage non-specialists in the provision of services. Historically, HIV testing had been provided in specialist settings, with a degree of mystique growing up around it.

> *GPs aren't terribly involved, but I look upon that as being a hangover from what took place in the 1980s... a cult grew up around testing and informed consent.* **D2male**

A number of the specialists recognised that providing support may help to overcome the perceived reluctance of other health care professionals to become involved in dealing with possibly complex medical needs outside their domain of experience. Some participants felt that unwillingness amongst non-specialists to take the initiative with regard to HIV testing was because they questioned their own expertise.

> *My sense is actually... I don't think it's necessarily "I don't want to know", but I think it is about "I'm not the expert ... there are people who can deal with this better than I can."* **V2female**

In general, participants shared a very strong desire to collaborate and to provide support and training to colleagues. Five participants cited the experience of setting up the processes for antenatal testing as a positive example of multidisciplinary teamwork to provide training and support to midwives, despite a perceived lack of management support. Similar support and training, it

was believed, could enable other health professionals to gain confidence and help to overcome a fear of being unequipped to deal with potentially challenging situations.

> *I think HIV can leave people... completely overwhelmed with everything. So it's getting support and saying, "Look, there is a support network when somebody is positive. You're not going to be left on your own with this positive person in front of you, thinking, 'Well, you're positive, what do I tell you?'"* **D2male**

Good communication was considered a key aspect of working well in a multidisciplinary team, especially when working across multiple sites. Being able to contact the relevant person by telephone when needed was seen as an important part of providing support, and some felt that knowing the support is available, even if it isn't actually used, is itself very important.

On the whole there was a strong sense of collegiality between health professionals, a sense of sharing the common goal of working in the best interests of patients, and a desire to provide support and advice to fellow professionals. There was considerable understanding of the difficulties that may be encountered by other health care professionals in providing HIV testing and care, and often this was accompanied by an apparently genuine attempt to see things from their perspective. Thus, rather than working in competition, their aim was to improve services and recognise the difficulties faced by other professionals and the constraints they face.

> *It's not about taking customers away but it is about supporting the service to enable more people to be able to come to be tested.*
> **V2female**

Although the majority of professionals were reluctant openly to criticise health worker colleagues, generally preferring to focus on the need to provide appropriate training and support, it was clear that some had encountered examples of inadequate patient care.

> *It is unfortunate, because some of the people that we pick up, late presentations who are African, have sometimes been missed by the GPs. They may have been going to the GP for ill health and for*

whatever reason the GP hasn't done an HIV test. **H2male**

It was perhaps as a consequence of feeling uncomfortable with criticising fellow health professionals that some participants were keen to emphasise that they did not wish to attach blame. In weighing these comments it may be important to consider the possible effect of the interviewer being known to be a GP (this is discussed further in 6.3.2).

> *I think there are opportunities [for GPs to offer the test more often] and I think GPs could do more, but I don't blame them for not, if that makes sense.* **D3male**

4.6.2. The role of primary care in HIV testing

On the whole, specialists working in HIV care saw benefit in working together with non-specialist colleagues to provide greater access to HIV testing for African people. There was a strong sense that other clinicians have an important role to play, most especially the general practitioner.

> *I think GPs have got a huge, valuable place in the small number of African people who they've got to know and have got a rapport with.* **D1female**

GPs are often the first point of contact with medical care and a person with symptomatic HIV disease might first seek help from their GP. Interviewees felt that this made it important for GPs to maintain a high index of suspicion, to be aware of the prevalence of HIV infection in African people, and to be sufficiently knowledgeable to be able to discuss and to offer an HIV test to symptomatic patients where appropriate

> *Because they [GPs] are the first point of contact you know with the patients. It is quite important.* **V1female**

Participants expressed mixed views regarding how GPs deal with possible HIV infection in symptomatic African patients, and how commonly GPs were likely to discuss possible HIV infection in such a case. Some participants felt that most GPs were doing this consistently well.

> *... there are a lot of GPs recognising that African people are, especially if they're recently over from Africa they are more at risk of HIV, are offering testing more commonly.* **H2male**

Others felt that HIV was more likely to be identified by GPs working in certain areas of the city, with more work needing to be done to raise awareness amongst GPs who were seeing African people less frequently in their surgeries.

> *I don't think that all GPs are kind of on board with that, inner city ones probably more so because they'll see more people. ... I think there's still quite a lot of work to be done.* **V2female**

On the whole, HIV specialists were generous in their appreciation of the challenges faced by GPs. They recognised that HIV medicine is a complex and changing field that may be difficult for the generalist GP to keep abreast of. A number of participants raised issues relating to confidence, suggesting that a lack of confidence may account for some GPs being reticent about undertaking HIV testing in their surgeries. However, generally they felt that most GPs had a basic knowledge of the disease that was sufficient for them to offer testing and to put in place referral to secondary care when appropriate.

> *Most [GPs] have a really good understanding of the basic problems, and a good appreciation of when to refer or who and how to ask.* **D1female**

Extending the role of primary care

A number of participants felt that an increased role for GPs in offering HIV testing to their African patients was a vital component of any attempt to increase the uptake of HIV testing. Some referred to the role of primary care as set out in the National Strategy for Sexual Health, which calls for HIV testing to be available in all GP surgeries, and felt that this was an appropriate way forward. Most believed that with suitable encouragement and support, many GPs would be willing to be more proactive in offering HIV tests to African people.

> *Looking at African communities, the potential for primary care, it could be that it's actually really key... I think it's a place that should be used as much as possible in HIV prevention, certainly*

> *awareness raising and the whole thing about trying to make testing more acceptable.* **P1female**

A particular advantage of increasing the involvement of GPs was felt to be the breadth of contact GPs have with a wide range of patients. A number of informants considered how the unique position of primary care could be utilised, for example in encouraging difficult to access partners of HIV-infected patients to come forward for testing. It was also felt that GP surgeries could be places in which to make HIV information more widely available, and that HIV testing in primary care might have a useful role to play in enabling HIV to be seen more like any other infection that might be picked up by the GP.

> *I think there's a massive role to be played by GPs... there is a big role for GPs and GP surgeries in terms of information about HIV, HIV being seen as an infection that people get, rather than this kind of massively stigmatised illness.* **V2female**

In addition to the discourses around GPs and their surgeries, some participants saw a potential role for other members of the primary care team, particularly practice nurses. These nurses, it was suggested, could receive appropriate training and be supported by specialists working within the HIV service. They believed that nurses would have more time to spend with patients, and that it might be useful for GPs in the practice to be in a position to offer African patients the opportunity to discuss HIV with a nurse. A consultant pointed to the potential benefits of having at least one person in the practice who had undergone training, not only in relation to HIV but also around relevant aspects of African culture.

> *... if they knew there is somebody they can go and talk to who's aware of their issues, I would see that as being something which would be incredibly helpful.* **D2male**

Being proactive – the new patient consultation

Most of the discourses around the current and potential role of primary care in HIV testing were initiated spontaneously by participants, and in general they were keen to encourage GPs to be more proactive in offering HIV testing. In

interviews where the subject was not raised it was introduced by the interviewer. Specifically, the interviewer explored participants' responses to a question about offering an HIV test opportunistically to African patients, and the possibility of this being done with all newly registered African patients. On the whole, the initial response to this idea was dominated by discourse centring on perceptions of racism (see page 131). However, even whilst continuing to express a degree of caution, the majority of interviewees felt that there were potential benefits. The emphasis was very clearly on the way in which the test was offered, the benefit to the patient, and on making it clear that the patient would be given a choice.

> *I think it's acceptable, I think it depends on the way that it's done. I think if it is part of a first visit check-up, I suppose it depends on the way it is worded as well. I think my gut feeling is that it is acceptable if you are saying to somebody: "You know, it's for your benefit that we're asking these questions."* **H3male**

A minority of participants remained uncomfortable with the concept of targeting offers of HIV testing through general practice regardless of safeguards. One doctor felt that because it was such a sensitive issue it would be preferable to discuss HIV testing with an African patient after there had been an opportunity to build trust, and therefore the first consultation was not the time to be raising this possibility.

> *I don't know how you can begin to universally offer some kind of HIV screen in general practice without appearing to be racist and in the time you've got. It could be perhaps part of a new patient medical, but there's a lot to cover in a new patient medical and I think you need to have gained someone's trust, and they've got to know you before you do that... It may be when you know the person and if you see them often enough to have got some kind of rapport with them.* **D1female**

Having expressed their concerns, especially in relation to being perceived as racist, most informants came to a view that offering an HIV test to newly registered African patients was appropriate given the recognised need. For some, more than others, it was even seen as 'important'

> *It would seem to me that that sort of thing, especially for people who've arrived quite recently from a country that has a really*

high HIV prevalence rate, it does seem to be an important thing to offer. **P1female**

4.6.3. Further aspects of improving uptake

Ensuring confidentiality

The need to ensure confidentiality emerged as important across the range of interviews with professionals. As already discussed (see page 121), specialists in HIV were sensitive to the stigma faced by African people known to be living with HIV, and to the consequent difficulties faced by many in relation to disclosing their status to others. Thus, professionals attached considerable importance to issues around confidentiality of patient details and for some this had particular poignancy because of previous experience of poor practice. Some were concerned about the levels of confidentiality maintained in general practice; some of those who worked in the genitourinary medicine clinic felt that they had a particular advantage because of the systems they used.

For a lot of African people there may be huge concerns about their confidentiality at the GP in terms who gets to know stuff and has access to their records... that's one of the things that makes this area quite unique in that it can offer a better type of confidentiality for there's better safeguards for confidentiality here. **H1female**

Most informants clearly felt that there was benefit to the GP being made aware of a patient's HIV status, even if that person had tested at another site, and patients were mainly encouraged to permit their GP to be contacted with appropriate information. However, occasionally there was experience of African patients being reluctant to allow this, and a suggestion that this arose from concern that it might affect their general medical care.

... being known that they are HIV positive they feel that that's going to affect their access to other general care, which is not necessarily for HIV. **V1female**

Normalising the HIV test

One of the advantages specialists perceived might result from extending the role of primary care was to make HIV testing more 'mainstream' and, as a result, help to reduce its associated stigma. In the early years of managing the disease it had been very much the preserve of specialists and, according to some interviewees, this had served to disempower other professionals and to increase the fear of the disease. It was generally felt that bringing HIV testing into general practice would help to change attitudes. For those clinicians who offer the test confidently and routinely it can become straightforward, and is little different to the myriad other tests carried out on a daily basis in general practice.

> *I think at the end of the day all of us, GPs, midwives, whoever, when you're dealing with patients you're always offering tests aren't you? Having to talk about difficult issues, and this is just another one of those. It's no big deal and at the end of the day as long as you know your facts, the reasoning why you're offering that test, that's it.* **M1female**

Further, it was thought important for HIV testing to part of an holistic approach to care. The emphasis, it was claimed, should be upon seeing HIV testing in the context of the needs of the whole person. General practice may be particularly well placed to set HIV testing within the context of a person's more general health needs.

> *I think it would have to be done in a kind of way that is looking at somebody more holistically, you know, in terms of their general health and that HIV is part of that.* **H1female**

Education and information – telling the benefits

As discussed previously professionals identified lack of knowledge about the benefits of early awareness of HIV status as an important barrier to HIV testing for African people (see page 123) and many returned to this concept in the context of general practice. It was felt that general practice was well placed to provide information and raise awareness about HIV with posters and information leaflets being especially valuable for newly registered patients.

> *... [use] information leaflets that can be given out at the new patient check... which is educational and informative, so that the person wouldn't feel stigmatised or picked upon, that would actually be something they might read afterwards.* **D1female**

Participants repeatedly stressed the importance of conveying the potential benefits of HIV testing to African patients. Many felt that it would remain difficult to improve the uptake of HIV testing whilst patients believed that HIV infection spelt almost certain death and remained unaware of the availability of antiretrovirals. Thus, presenting clear information was considered key to convincing a person that it was in his or her own interest to discover their HIV status.

> *I mean if you don't see the benefits it's hard to convince someone that they will be better off knowing they're positive.* **D3male**

The way in which this information is given was thought to be important. Emphasis was placed upon the words used, in particular wishing to ensure that information is presented in a factual and non-judgmental way. Whilst many informants saw written information as a useful way of conveying information, one key informant emphasized that communication needs to be culturally appropriate, and that written information alone may be insufficient.

> *It should be more than written information. In African cultures oral tradition is the thing. It is more respected, it is more taken in and it's more effective, rather than watching a video or you know, reading a little leaflet.* **V1female**

It was generally felt that a discussion between the GP (or nurse) and the patient was an effective way of encouraging an African person to consider HIV testing, although this could usefully be supplemented by written information before or after the discussion. The importance attached to communicating the benefits of timely testing was linked to a clear sense that very few patients declined the test if an appropriate discussion had taken place. Thus, opportunistically discussing the benefits of testing within a primary care consultation was seen by many as an important way of increasing the uptake of HIV testing.

> *On the whole I don't think there's many that do [decline the offer of a test]. I think if you're able to discuss with somebody the benefits of testing or why we're actually asking somebody about testing, I think on the whole that there is a large uptake of HIV testing.* **H3male**

Other strategies to raise awareness of the importance of HIV testing were also mentioned; in particular the need to work with African people to encourage them to take messages about HIV and the benefits of testing into their community. The Health Promotion Specialist emphasized the importance of persuading whole communities of the benefits of early HIV testing, in tandem with working at an individual level.

> *We have to work really within the communities too, so that they will accept the services that are actually offered to them, see the use of them, see the relevance to themselves.* **P1female**

4.7. Concluding comments

This chapter has outlined the range of themes emerging from the key informant interview data in relation to HIV testing in African people living in the UK. Within these themes, professionals' discourses on the perceived barriers to the uptake of HIV testing have been highlighted and attention has been paid to views on how these might be ameliorated.

Initially the approach to these interviews with professionals was as a source of facts or information about the field of study. However, these data clearly reveal that professionals' views are not objective and neutral; they are not separate from the professionals' own sense of self and personal beliefs, but arise from social interaction with African people and the meanings they attach to the attitudes and behaviour they encounter in these relationships. The data show the extent to which there has been deep personal engagement at a social, emotional, psychological and political level for many of these informants. Indeed, at least in part, the imperative for further action arises from compassionate concern.

The breadth and depth of the discourses, perhaps particularly the extent to which professionals engaged with attempting to understand the perspectives of their patients, highlights the need to move beyond a traditional view of the professional relationship between clinician and patient, or professional and client, as merely functional in which information is provided or treatment and care is given. Indeed, there was little that was dispassionate in these accounts, and it was clear that at least some consultations and meetings with African people had profoundly affected these informants.

The professionals included in this series of interviews represent a broad range of expertise and experience, and the data reflect the varying perspectives they bring. However, whilst the data reveal different emphases, on the whole there is considerable agreement across the informants in relation to the key themes.

Discourses around possible ways of overcoming the perceived barriers to HIV testing were extensive and particularly focused on possible roles for primary care. This chapter, above all, points to the need for improving the uptake of HIV testing amongst African people and the commitment of these professionals to realising this objective.

> *[HIV] has such life changing consequences... so I think we must do it. We must do it and tailor it to local population.* **P1female**

The broader implications of the themes emerging from the data will be considered in Chapter 6 where they will be discussed in the light of the data arising from the interviews with African people. The interview data from African participants will be considered in the next chapter.

CHAPTER 5. THE VIEWS OF THE AFRICAN PARTICIPANTS

5.1. Introduction

This chapter will present a descriptive and interpretive account of the data obtained from the in-depth interviews with African participants. The topics covered in the interviews were wide-ranging, inevitably extending beyond issues around HIV testing. Thus, for example, participants who were living in the knowledge of being infected with HIV led the discussion into areas beyond the specific questions addressed by the study. Such discourses were helpful in illuminating the research question and provided further context, as the researcher followed the participants into these areas and permitted them to shape her interpretation of the interview data. However, this chapter will focus on the primary research question, which addresses the barriers to HIV testing for African people living in the UK and considers ways to improve uptake of testing.

In-depth interviews were conducted with 26 African participants from a range of countries in sub-Saharan Africa and of known and unknown HIV status. The Appendix contains details of the demographic characteristics of the sample and a brief profile of each participant.

Presentation of the results

The structure of this chapter is based around the five key organising themes that emerged from the data (see Figure 11). Each of these themes and the various sub-themes within them are illustrated by quotations from the interview transcripts, selected to reflect the full range of views expressed.

Figure 11: Key organising themes

- Complexity, competing priorities and the struggle for survival
- Culture and beliefs, experience and knowledge: the ongoing influence of Africa
- Fear of disease and of others: stigma, risk perception and denial
- Opportunities for testing: how, why and when?
- Improving uptake: knowledge, targeted testing and the role of primary care

Participant identifiers will be given with each quote. The identification codes indicate the participant's country of origin, HIV status and gender as summarised in Figure 12 below. Thus, for example, the identifier 'Zi2H+male' represents the second participant from Zimbabwe and indicates that the participant is male and known to be infected with HIV.

Figure 12: African interviewee identifiers

Country of origin	**HIV status**
B = Botswana	H+ = HIV positive
Ca = Cameroon	H - = HIV negative
Co = Congo	U = Unknown
I = Ivory Coast	
K = Kenya	
M = Malawi	
Na = Namibia	
Ni = Nigeria	
S = South Africa	
Za = Zambia	
Zi = Zimbabwe	

5.2. Complexity, competing priorities and the struggle for survival

The issues surrounding HIV testing for the African participants are not distinct from the rest of life; they cannot be conveniently separated from the sometimes

messy and ongoing personal struggles faced by the participants. It was clear throughout the interviews that many respondents had survived difficult past life experiences that continued to impact upon their psychological state. Life in the UK was felt to be far from comfortable, posing many difficult challenges, struggles and future uncertainties. The complexity of the various and difficult demands faced by participants emerged strongly across the range of interviews and provides the context within which barriers to HIV testing are set.

5.2.1. Background: the stories behind being a migrant

Reasons cited for migration to the UK broadly fell into three main groups: economic, political and educational, but often these were not mutually exclusive. Many did not intend to remain in the UK on a permanent basis, or at least that had not been their original intention, and most held a desire to return to their families and their country of origin at some time in the future. Many of those who came by choice, rather than primarily to flee persecution, arrived with hopes of a better life with greater opportunities, and there was a sense of disappointment that their expectations had not been met, with life being much more complex and difficult than they had anticipated.

Studying in the UK

A number of the African participants had a very high regard for education and saw educational opportunities in the UK as very attractive. Courses being undertaken by participants included music, media studies, accountancy, nursing studies and tourism, with most funding their own studies. However, many participants felt their hopes and high expectations had not been met, and the financial implications had sometimes not been fully understood before arrival. Despite such disappointment participants conveyed a resilience and adaptability to changing circumstances.

Political reasons for leaving home

For a number of African participants the motivation to leave their country of birth was primarily related to political instability at home. For some, the political situation had impacted considerably upon them, resulting in their seeking asylum in the UK. Others were motivated by a general impetus to seek a better environment in which to live.

> *I came to Bristol because there are problems in Zimbabwe: the economy and politically and everything there is problems. There is civil unrest or economic disorder. I would say that's why most of us are coming over to England, because of the political situation... it really affected me and my children, so I just thought maybe if I leave for this country things would be better for me and my children.* **Zi10H+female**

Amongst those who had experienced a more direct impact upon their work or family life were a Zimbabwean lawyer who felt that his work had been under surveillance and a Zimbabwean musician who described being forced to leave the country because his music had been viewed as political. A number of participants told harrowing stories of the direct physical and psychological trauma they had experienced in their home country. These accounts appeared to exert a powerful influence upon how respondents were able to cope with and manage their lives in the UK. For one Kenyan woman, tribal and family conflict led to appalling events that resulted in the murder of her husband and the rape and death of her twelve-year-old daughter.

> *One day the Mongeki came, many people...that is when they raped me. They wanted to circumcise me, and my husband came... When he was helping me, they shoot him in the head and he died. And so my husband died like that. They came another day when they wanted to circumcise my daughter and they raped her, they raped me. There were seven men, they raped me, they raped my daughter and my daughter died afterwards... I was very, very, very sick. I was bleeding. I had wounds inside there because they inserted gun inside my vagina and they did bad things to me. I was very, very sick, I was confused ... I wanted to kill myself.*
> **K1H+female**

For others, being associated with opposition to the government had resulted in violence and persecution, with subsequent distressing consequences and ongoing psychological impact. Thus, one woman from Zimbabwe told how being a member of an opposition party denied her access to a 'ZANU-PF' card, which prevented her from buying certain goods and made it difficult for her to provide for her children. One participant from Cameroon had sought refuge in the UK following her escape from custody, telling a dramatic and upsetting tale of her own arrest, detention and beating; fleeing the country and leaving her children behind. Her husband's execution, the treatment she had suffered and concern for her family continued to be deeply distressing and this was clearly evident in her interview account.

Economic necessity and responsibilities

Many participants felt a financial responsibility towards family members in their home country and for some this was the primary motivation for migration to the UK. For example, one South African man had been working in manual factory jobs for a number of years in order to support his mother and four younger brothers at home and, in common with others, felt that particular responsibility fell upon the 'first born' son. Others were parents financially supporting their children who remained in Africa, believing that money earned in the UK was substantial in terms of the economics of Africa and could make an important difference to their families at home.

> *Things are quite, quite difficult [in Zimbabwe] and I am the only breadwinner in my family whereby they are all looking at me.*
> **Zi12H+male**

Earning money to provide support for family at home was sometimes prioritised over health care. Thus, one woman who was supporting children in Africa had cause to think about her own possible exposure to HIV following the death of a friend from AIDS related illness, but it was not until much later, when she became ill herself that she was tested for HIV.

> *I was just concentrating on my job, I was concentrating on*

sending money back home, you know, with my day-to-day life.
Zi10H+female

5.2.2. Facing the realities: living as a migrant in the UK

Living as a migrant in the UK presented many challenges and struggles; many participants found it difficult to be far from home, family and all that had been familiar. When set against a background of unfamiliarity, isolation and the struggles of day-to-day life in the UK, health considerations were often not seen as a priority.

Family separation and worry

During several of the interviews it emerged that family separation was a difficult issue and participants struggled with the emotional burden of enforced separation from sometimes very young children. Thus, one woman spoke of the pain she felt in not having seen her four year old child for over two years, and of not knowing when she might be able to see him again.

It's difficult. It's just terrible. We're still away and you know … he cannot come because we were not granted the indefinite leave.
Zi5H+female

Telephone conversations and even email communication were said to help alleviate the emotional pain of separation although for those with family in the more rural parts of Africa this was often not feasible. Anxiety for the health and safety of family at home made the separation more difficult to bear. One Zimbabwean participant disclosed that his young son had died of presumed AIDS related disease in his absence and several others spoke of health worries for their children. Concerns for family were particularly pressing for those who had left their country of birth because of persecution.

It's when they shot [my husband], sorry … (crying), it's when they shot him that they, they, they rang my family to come and take the body (pause 10 seconds)… And I have three children, I have three children... (crying)… They are still in Cameroon. They are with my mother but … I don't know if they can attack them and I don't know if they are in danger. **Ca1H-female**

Work and accommodation in the UK

Issues around employment posed numerous difficulties and consumed much time and effort. Whilst only one participant spoke explicitly about working illegally it was implicit in a number of other accounts that financial pressures led many to contravene the stipulations of their visa. Many of those who had intended to study in the UK found it necessary to take work to fund their course and living expenses and, as mentioned previously, many were committed to supporting family at home. Participants were often engaged in several jobs, sometimes working long and unsociable hours to earn sufficient to support themselves and their families. Most worked in unskilled or semi-skilled temporary jobs, often felt to be below their abilities.

> *Sometimes I do these crap jobs, you know, just here and there.*
> **B1H+male**

Concerns around suitable employment were closely associated with issues of accommodation. The majority of interviews were conducted in the participants' homes and the standard of accommodation was generally poor. Many participants lived in a bed-sit or a single room in shared hostel accommodation and some had to share their room with a young child or children. It emerged that it was fairly common to be forced, for financial or other reasons, to move accommodation on a frequent basis. The whole matter of feeling settled in a safe and comfortable home was one that caused considerable concern.

> *I just thought I don't know what I'm going to do. I'm really worried about accommodation and stuff.* **Zi3H+female**

Immigration status

Issues around immigration status were prominent within the interviews. In cases where the participant did not raise the subject spontaneously, the interviewer asked a general question about the person's intentions and ability to remain in the UK. Three participants had permanent residency or British citizenship by marriage, three had been granted refugee status and the majority were either on

time limited student visas or were still in the process of seeking asylum or 'leave to remain'. For many it had been a dominant issue, consuming large amounts of time, emotional energy and worry. Some of those who had arrived in the UK seeking asylum had been dealt with under the National Asylum Service and had been forced to move around the country before arriving in Bristol. Negotiating the asylum system had been especially difficult for some and for one participant had involved a period in a detention centre following the rejection of her initial claim. Struggling to be recognised as a genuine asylum seeker was associated with anxiety, stress and a real sense of frustration and injustice.

> *They are sure they can't believe my story. They don't think that I can be in danger in my country. Even when I told them that my husband has been killed there, and I sent to them a burial certificate, hospital report, everything, they say that in Cameroon people can make fake documents. I don't understand. How can I make a fake document for my husband who is still alive? So I am just waiting [to see] if the solicitor can get something positive.*
>
> **Ca1H-female**

It was clear that the issue of immigration status and its impact upon place of residence, ability to work, access to funds and future plans to reside in the UK, was a major consideration for many of these informants. This provided part of the complex backdrop to the experience of living as a migrant in the UK, which in turn impacted the likelihood of accessing health care and voluntary HIV testing.

Multiple problems: depression and despair

For some participants, it emerged that their experiences as a migrant in the UK had brought them to the point of despair at times. For one participant it felt like his life was falling apart.

> *When I came to Bristol, basically I think my life just fell apart, you know, everything...no jobs, no this.... break-up of marriage, probably mid-life crisis. So I have, like tried to sort out myself.*
>
> **M2H+male**

For some participants, the difficult circumstances they faced left them feeling out of control and trapped. One woman described the abusive relationship she suffered from her husband who, being often drunk, would beat her regularly. She felt unable to escape from this relationship because of her dependence upon him whilst her immigration status remained uncertain.

> *I was referred to the domestic violence whatever. It was really difficult because we applied for our visas. ...G is the one who applied so I was sort of like G's dependant, you see. So we had one application and I am facing domestic violence, I can't go anywhere, I can't do anything because my passport is not with me. It's at the Home Office, so... it is difficult.* **Zi5H+female**

The complexity of this woman's problems made her life feel impossible to her. She faced domestic violence, an uncertain immigration status, separation from her young child in Zimbabwe, financial and accommodation concerns and was working illegally. Whilst other participants spoke of 'feeling low' and of being depressed, this particular participant was alone in speaking of an actual attempt to end her life in which she had taken an overdose of antidepressants. This woman's experience is perhaps the more extreme end of a spectrum of difficulties and struggles faced by African people. Even so it was generally the case that issues relating to health, in particular decisions around voluntary HIV testing, could not be separated from a complex background of multiple challenges.

5.3. Culture and beliefs, experience and knowledge: the ongoing influence of Africa.

5.3.1. Knowledge and experience of disease

Across the range of interviews, knowledge and experience of HIV was shaped by the experience of HIV in Africa, a setting in which treatment was generally limited and often unavailable. Participants who had undergone HIV testing in the UK, and even more so for those who had subsequently been diagnosed as

infected with the virus, had enhanced knowledge of HIV gained through information received from health care professionals in pre-test discussions, post-test counselling and subsequent treatment. Therefore, to understand more fully the processes involved prior to and at the time of testing, participants who had tested positive for HIV were asked to reflect upon their views and knowledge prior to direct engagement with HIV specialist health care providers.

Prevalence of HIV in Africa

In response to a general question about the extent of HIV related disease in his or her country of origin, each participant provided a detailed account of the devastating impact of HIV. Reflecting upon the experience of living in a country with widespread infection, it was felt that HIV was 'everywhere' and could, and often did, affect people from all parts of society.

> *You don't even know who to trust, because it's everywhere, it's just everywhere. You're wondering. Maybe four people in ten people will be affected.* **Zi1H-female**

Although all participants were aware of the presence of HIV in Africa, and had seen its consequences first hand, they commonly expressed that it was often denied or not spoken of openly. There was often an assumption about AIDS being the cause of illness and death, and many informants spoke of assuming that people they knew had died of AIDS related disease, rather than having been told directly. They surmised that there might not have been a definite diagnosis available, but more often it was related to an attempt to cover up the true diagnosis and multiple examples of this phenomenon were given.

> *...they'd be like "maybe it was some kind of like natural kind of disease or something", but it was AIDS! They were denying the fact that it was AIDS because if you die of AIDS it's something like, you know "Oh, he died of AIDS." It's like there is a cover up.* **S1Umale**

Personal experience of HIV and AIDS deaths in Africa

Despite the strong sense of HIV and AIDS not being fully acknowledged in the illness and deaths of many in Africa, the participants had a great deal of personal experience of the disease in their various home countries. Most had lost at least one person who they knew well and many had lost close friends and family members. One female participant spoke of the death of both brothers and a sister. Others spoke of recent distressing bereavements of close friends and family members: a sibling and in one case a child. Many had experienced the death of several people in their wider circle of associates: in the community, at school or college and in the workplace.

> *There is somebody who's dying every day, being buried in the local area. ... We used to say, if you stay in your office from Monday to Friday, you're just going to bury somebody, that week...every week you were burying somebody you know. So everybody is in fear because you don't know whether you are affected, you don't know who's going next whether it's your brother, your sister, your child, yourself, your wife, your friend.*
>
> **M2H+male**

Treatment and testing in Africa

The participants' experiences of the impact of HIV and AIDS on friends and family were largely gained in their country of origin, and therefore substantially shaped by the medical and care services available in those settings. It emerged from a number of interviews that knowledge of the disease, and experience of its often relentlessly devastating impact, profoundly affected the way in which the disease was approached and perceived in the UK. Thus, for example, one Zimbabwean woman known to be infected with HIV continued to be affected by her recollections of the suffering endured by an HIV infected woman known to her in her home country.

> *She was just bones... they took her in a wagon, with donkeys and whatever, going with her to clinic. She couldn't walk, she couldn't do anything... it's like every time I think of her my heart sinks because she was so skinny.* **Zi5H+female**

Some participants displayed no knowledge of any treatment to modify the course of the disease, and many of those who were aware of treatment had gained their knowledge subsequent to their own diagnosis.

> *I don't think a lot of people know like there is treatment, although the treatment that is available is only because of the England system. Myself, I didn't know about this medicine up until when H explained everything.* **Zi3H+female**

Having knowledge about antiretroviral drug treatment, together with availability and accessibility of those drugs were major contributory factors to the decision to test for HIV. When there is no awareness of treatment, or where treatment is unavailable, negative experiences of having seen many people die led some participants to resist HIV testing.

> *There's really no point if you know [that you are HIV positive] and you know you are not going to get help. Then I think it might have a psychological impact on you. You might just give up and start to deteriorate and just die.* **Zi7H+male**

The level of awareness of the existence of antiretroviral medication varied considerably across the participants. Some were aware of the use of drugs which could decrease the likelihood of transmission from mother to child because they were being used in their country of origin, but had no experience of the availability of antiretroviral drugs to prolong life in those already infected with HIV. Others were aware of the drugs being available but their cost in Africa had largely put them beyond the reach of ordinary people like themselves.

The most extensive knowledge about HIV medication was generally displayed by participants who had been diagnosed as carrying the virus and who were now receiving treatment. These participants had largely gained their understanding and knowledge since their diagnosis, which for many had been subsequent to the development of ill health. One notable exception was a participant from Zimbabwe who had proactively sought voluntary HIV testing in the UK and knew he was not infected. His knowledge of HIV and of antiretroviral medication was more accurate and extensive than most others, had

not been gained from health professionals in the UK, and appeared to be a motivating factor in choosing to be tested. It is notable that this man had worked as an accountant for the Zimbabwe National Family Planning Council, during which time he had received training about HIV, in order to offer initial counselling to clients when other professionally qualified staff were unavailable.

Most of the participants had little direct experience of HIV testing in Africa and had not been tested in their country of origin. Even so, perceptions of the way in which HIV testing is conducted, and its cost and its availability in their country of origin, impacted upon attitudes to HIV testing in the UK. Generally HIV testing in Africa was not widely or freely available.

> *The test is not free, and for a man who cannot afford to eat properly, I don't think even if he has 100 naira, which is less than 50p anyway, and if he needs that to survive for two days, and you tell him to bring 80 naira for a test, he will tell you he hasn't enough.* **Ni1Umale**

However, some informants felt that it was not cost alone that made HIV testing in Africa particularly difficult. In Cameroon, for example, free HIV testing was available on World AIDS Day, yet the process of testing and the way in which discussions around testing took place were themselves off-putting.

> *... and the way she [the nurse] behaved - "You came here for the test! Ah, let's go there" and when we went to the room she closed [the door]. "I don't want that you cry, people see you screaming when you get the result." She make me scared... I was in a panic because [she had said] "I don't want people to hear you crying when you get the results". It was why I refused.* **Ca1H-female**

Knowledge of the disease

Knowledge of the disease was substantially shaped by participants' experiences in Africa where HIV infection frequently resulted in death from AIDS. Thus many participants recognised little distinction between HIV and AIDS.

> *They asked me to check me for a disease. I didn't know it is HIV because I only knew it as AIDS... I only knew there's AIDS, and when you get AIDS you die. That is what I only knew.*
> **K1H+female**

A Kenyan participant who knew he was not infected reflected that his decision proactively to seek testing was in part accounted for by his knowledge of the disease. In particular he felt that his knowledge of the distinction between being HIV positive and having AIDS marked him out as different from other African people.

> *I think [African people] don't know the difference between HIV and AIDS; so they assume if someone is prognosed to be HIV positive then he is definitely someone exiting there. That is like a death to them.* **K2H-male**

This view was borne out by others, and its persistence amongst African people once they had moved to the UK appeared to have a direct impact upon the attitude to voluntary HIV testing.

Closely related to the way in which participants perceived the distinction, or lack of it, between HIV and AIDS was their understanding of disease presentation and awareness of hidden infection. It emerged that many participants did not know that infection with HIV often has a substantial asymptomatic phase. Some HIV infected participants were aware of this but this knowledge had mainly been acquired after they had been diagnosed.

> *I think this HIV/AIDS is sort of deceitful. You feel OK, you don't feel anything even though the virus is living in your body. So you say to yourself "Oh I am fit and strong, I weigh this much, my skin is OK, so I am OK, I'm not ill." In actual fact you are already infected... that is one big problem, because people think they are well and they don't have the virus.* **Zi10H+female**

Without exception, participants known to be infected with HIV had been tested either through the antenatal programme, because their partner was known to be infected or because they had become unwell. None of the HIV infected participants had proactively sought HIV testing whilst asymptomatic. In contrast, participants who had a negative HIV status had sought testing whilst they were well, partly because they were aware that early HIV infection might not declare itself through symptoms.

Everyone looks healthy, but you don't know inside, yeah, you don't know inside.
Zi2H-male

Those who had been symptomatic prior to being diagnosed with HIV infection often accounted for their symptoms in other ways, at least in part because they did not recognise their symptoms as similar to those they had seen in HIV related disease in Africa. For example, one man who was feeling generally tired and weak put his symptoms down to stress and did not consider that he might be infected with HIV.

I wasn't thinking about it [HIV] cos I thought I would see symptoms coming out ... because I had no signs of any related to that I wasn't thinking about it or expecting it... these herpes and these other effects; this coughing and stomach pains and diarrhoea, running stomach. They are such things that I was expecting.
Zi12H+male

Even the considerable loss of weight and general malaise experienced by a Malawian participant was not recognised as serious disease, and it took further progression of the disease and admission to hospital before she was tested for the presence of HIV.

What happened was I was losing weight but I didn't recognise, didn't bother, and I just thought maybe it was because of stress... but it didn't bother me, I just thought, "Life in England is hard... I'm juggling between college and work, so life is just hard."
M1H+female

Awareness of risk factors for transmission

Discussion around the risk factors for transmission of HIV was introduced by asking a general question about the ways in which infection could be transmitted. Without exception, all of the participants spontaneously referred to the possibility of the virus being transmitted during sexual intercourse. Many participants associated an increased risk of transmission with a greater number of sexual partners, whilst a few participants pointed out that it was not only the number of partners but also the likelihood that any individual partner had been exposed to the virus.

> *[The doctor] asked, "Have you been sleeping around?" I said, "No, but you never know the person whom you sleep with; how healthy is she?"*
> **Zi2H-male**

Other routes of transmission were less consistently raised. Some mentioned exposure to infected blood, most notably through transfusions and contaminated needles. Generally, informants did not consider that transmission of the virus took place through social contact with an HIV infected individual, although one participant stood out as holding a contrary view.

> *You need to take care of yourself... if you go to the bar ... you need to be careful which glass you drink. You can catch disease.*
> **I1Umale**

5.3.2. Beliefs: health, religion and perceptions of HIV

Health Beliefs

The health beliefs of the African participants emerged as a powerful influence on their health seeking behaviour. Some participants highlighted that Western approaches to healthcare were different to those in their home country, and that there was sometimes reluctance to access doctors in the UK as a consequence. Participants who had been diagnosed with HIV had generally delayed accessing medical care, and this was not peculiar to HIV related symptoms. More generally, it emerged that African people perceived themselves to rely more on 'natural' healing than medical intervention.

> *African people, most of them don't believe in doctors because back home you've got these traditional doctors. So sometimes it's hard for us to just go straight to a doctor. If it's something like I've got a wound, I'll just want it to heal itself... sometimes we will go to see the doctor when it's too late, when the treatment can no longer slow down the AIDS. We're not as quick as Europeans or English when it comes to seeing the doctor.* **S1Umale**

African herbal remedies continued to play a part in the system of health beliefs for some participants. One man from Ivory Coast spoke of his mother being a traditional healer, and of her having used sheep's horn and herbs from the forest

to make his hair grow. The continued belief in the value of African traditional medicine was underlined by their use in the UK. Thus a Malawian woman who had been diagnosed as infected with HIV initially used African herbs which she had sourced from home.

> *... using African herbs, which I did send for [at] first ... I spoke to K and he said I shouldn't be using like them herbs whatsoever because they can affect sometimes the treatment.* **M1H+female**

Although the ongoing influence of African traditional medicine emerged clearly from many accounts, it was also evident that most participants were willing to engage with Western medicine.

Spiritual Beliefs

There was extensive discourse in a number of interviews around the practice of witchcraft in Africa, especially its expression in relation to HIV. A number of participants felt that these spiritual beliefs and practices continued to exert influence on African people living in the UK. Many participants spoke of the common association in their various countries of origin between HIV/AIDS and supernatural beliefs about being cursed or bewitched. Participants who reflected upon this commonly linked it to unwillingness by some African people to acknowledge that the illness being encountered was HIV related.

> *If someone is ill, they never want to admit that you are suffering from AIDS...People think of witchcraft and whatever. You can just die or you can be very ill and then they say, "She was bewitched by this uncle or this aunt, this whatever."*
> **Zi5H+female**

A Zimbabwean participant explained that in his home country, the belief in witchcraft and evil spirits remained common, and that he had personal experience of its impact on people's thinking, including his own.

> *If you go to the witchdoctor, he will tell you things that actually happened and things that will happen and sometimes it actually happens and you start to think, after all maybe there's powers, supernatural powers that are around that actually controls people's lives.* **Zi7H+male**

Although he perceived that for African people living in the UK, *'being away from their families and relatives it becomes less and less'*, he felt that these beliefs did persist to some extent and accounted for the delay by some African people in seeking medical help. Further, his view was that this was equally true for well-educated people like himself.

While the influence of witchcraft may be less for African people who have been away from their country of origin for some time, it was clear that for some participants, continued contact with family at home led to ongoing exposure to these beliefs. Thus one Malawian woman, diagnosed with HIV infection, had been told by her mother that her ill health was a result of witchcraft.

> *[My mother] was just, "Oh maybe you have been bewitched. I said, "Mum, come on. It's my blood. I have been diagnosed. And I'm lucky to be here that I'll be starting treatment." But she still won't see it... It was like HIV is a force.* **M1H+female**

However, despite these apparent protestations, it subsequently emerged from her account that prior to being tested she had mused upon the possibility that her symptoms might be the consequence of *'being bewitched'*.

Belief in God

Belief in God emerged as a strong theme across the interviews and the great majority of participants expressed religious beliefs. Most identified their religious belief as Christian, with one professing the beliefs of the Seventh Day Adventist Church. Mostly these participants identified with, and many regularly attended, a variety of Protestant churches, whilst a minority was Catholic.

> *There are a number of churches, African churches here in Bristol. Really you see a lot of people; a lot of African people go to church. They really go to church.* **Zi2H-male**

It has been demonstrated previously that African spiritual beliefs, including witchcraft, continued to feature in the belief systems of some participants. Such traditional spiritual beliefs often co-existed with belief in God. Thus, the woman

who spoke of her commitment to the Seventh Day Adventist beliefs had earlier in the interview expressed her own fear that she might have been bewitched.

These frameworks of faith were felt by participants to be important to the conduct of their lives and a source of strength particularly for those participants who were HIV positive.

> *You really feel sort of comforted you know. It really comforts me and I am positive about everything else.* **Zi10H+female**

Some participants experienced the sense of community through attending church to be helpful; being with other people could be a distraction from dwelling on problems.

> *If I go to the church and meet other people and talk and talk, all those things they go off and then suddenly when you're alone again, they come back again. You start thinking hard which is not good for me, because when I'm thinking hard, I easily break down and I think of so many things.* **Zi4H+female**

Despite the benefit of talking to and being with others, it is notable that this woman, along with several other HIV positive participants, did not discuss their HIV status with others in their church community and therefore did not receive support and help from this source to meet their specific needs.

A further dimension of spiritual belief in relation to HIV testing raised by some participants was the belief that religious faith was protective against disease and sickness. One Kenyan man expressed frustration with his fellow country people who, he claimed, often said they believed *'God cannot let me have it'*. He went on to relate this attitude to the way in which HIV testing was considered.

> *They say, "No me, me I got no AIDS. Just I believe in God, I got no AIDS, and that's it." And that is why I have been trying to tell people that it's not about God, it's a fact if you have AIDS or if you don't have it.* **K2H-male**

Beliefs about HIV

Participants' attitudes to HIV and testing for the virus were affected by many of their general health and spiritual beliefs. However, the interviews also revealed the existence of beliefs more specific to HIV. One commonly held belief about HIV was that it was a form of supernatural judgment or divine punishment.

> *It's really just like if you've got HIV, they just think, "Oh you've got your punishment and that's it."* **M1H+female**

Within the interviews participants commonly reflected upon the beliefs they had encountered in Africa. Prominent amongst these was a persistent belief that HIV and AIDS do not exist. Whilst none of the participants identified with this view, there was often acknowledgement that it was widespread and not limited to uneducated people; even trained nurses were known to deny the existence of HIV.

An explanation for some of this thinking was given by a number of participants who spoke of HIV and AIDS in Africa being seen as a Western conspiracy. These beliefs ranged from denial of the existence of a disease at all; through to believing it was a Western construct to limit African childbirth by enforced use of condoms, or a way of gaining money from selling western drugs to African nations.

In much of the discourse around HIV beliefs it was clear that the participants had been exposed to many supernatural and other beliefs that related specifically to HIV. Some of these did not appear to influence the beliefs of these African people, for example the practice, mentioned by several informants, of HIV infected men having sexual intercourse with young girls in order to effect a cure. Other beliefs commonly held in Africa, such as the 'Western conspiracy' belief, and the reliance on supernatural forces did appear to have at least some influence upon the thinking of African people living in the UK and their willingness to undertake HIV testing.

> *Most of them they like to leave it to some supernatural thing. They don't want to have the test.* **K2H-male**

5.3.3. Cultural influences: gender, sexual behaviour and relationships

Cultural aspects of gender

A prominent theme that emerged across the interviews, especially those with African women, was the continuing influence of African cultural views on gender roles and behaviour. Many of the women talked about the power imbalance between African men and women. In Africa the women had commonly felt dominated and less powerful.

> *Most men behave like...I don't know...they are the leaders of everything and they can say anything, they can do anything, and they cannot be instructed about anything by a person.*
>
> **K1H+female**

Although this subject was raised by some African men, with one claiming that as a man it was right that he should do as he wanted, it was the women who spoke most often and most extensively on the subject.

> *It only depends on yourself. You're the man, what do you want to do?*
>
> **I1Umale**

Much of the discourse around the gender power imbalance arose in the context of discussion around current practice in Africa. However, it was clear that some of the women continued to experience its influence in the UK. It emerged during one interview that the participant, a married Zimbabwean woman, had taken part in the interview without her husband's knowledge and felt that he would not have permitted her to participate. She expressed anxiety that if he were to find out he would express his anger in violence towards her. It was for the same reason that she had been to the African women's support group on only one occasion and had deceived him about her whereabouts at that time.

Sexual behaviour and gender

According to the participants, attitudes to sexual relationships were often different for men and women. It was frequently felt that African men engaged in

multiple relationships, even when married and that this 'unfaithfulness' was to some extent an expression of culturally defined images of maleness.

> *[Zimbabwean men] are highly unfaithful... Maybe that's a way of proving they are men who do as their culture, I don't know, but they are unfaithful, they are very unfaithful.* **Zi10H+female**

This behaviour was related by a number of participants, both men and women, to being African, and was thought to be different to the behaviour of the indigenous male population.

> *English men are different from African men, because African men always think that they should have like two or three partners.*
> **Zi1H-female**

Cultural and gender related attitudes to condom use

Many of the women spoke of difficulties in negotiating safer sex, framing this within the context of male power and dominance. Thus, whether or not a condom was to be used was frequently referred to as the man's decision and under his control. Within a marriage relationship it was asserted that, even knowing that the male partner was having frequent affairs, it was often impossible for a wife to insist her husband use a condom despite feeling that she was being exposed to possible HIV infection. For African women living in the UK these attitudes continued to have an adverse impact, especially if returning to Africa where these views remain prevalent.

> *Men impose it on women to say, "If you are my wife, don't mention anything about a condom." If you mention a condom, he's going to beat you up...Like my sister went back home this year when I had already tested positive. So I said to her, "What are you going to do? You have been separated from your husband for a year now, are you going to use a condom or not?" She said, "I'm scared to mention that issue to him."* **Zi10H+female**

According to many of the participants, the difficulty women faced in negotiating condom use was not overcome by living in the UK. What was seen as a culturally determined issue persisted in the relationships between African men and women in this country, with it frequently being seen as male 'refusal' and female 'lack of

choice'. Condom use, according to female participants, if it happened at all, was only likely to be agreed to on the first few occasions of sexual intercourse.

> *In my culture if you meet somebody [you] use condom for one day, the man refuse to use it more than twice, so I haven't got much choice.* **M1H+female**

Most male participants claimed to be in favour of using condoms themselves, whilst at the same time suggesting that other African men did not share their views, even suggesting reasons why this might be so.

> *I know African men they don't like to [use condoms] they normally call it it's like eating a sweet with its wrapper on it. Most of them don't fancy the idea of using a condom, but I had no problem with that.* **K2H-male**

Sex as a taboo subject

Discourses around sexual activity and sexual history were prominent features of all the interviews. The extent of participant engagement in these discussions was remarkable given the cultural backdrop of sex as a taboo subject within many of the settings in which they lived prior to arrival in the UK.

> *It's like almost a taboo...a taboo, yeah. You don't talk about sex matters... It's not like here in the Western world where sex is probably mentioned on the TV more than fifty times a day.* **K2H-male**

These African participants acknowledged the ongoing influence of African culture upon the way they felt about discussing matters of sex. With health professionals it was generally felt that discussion of sexual matters became easier with time.

> *It was a bit difficult because when I registered with the doctor, she was asking me, "Are you having sex?" I just looked at her (laughing). And I said, "What?" And she said, "Oh, are you using any contraception?" But I just answered her very quickly and then I thought of something straight away because I didn't want to keep on saying about it.* **Zi3H+female**

Some participants noted that sex being a taboo subject might be a barrier to HIV testing. Discussing sex and related matters was considered impossible in public, or with friends. However, it was clear from the extensive interview discussion about sexual matters and HIV with the following participant that she was able and willing, in common with the other interviewees, to engage with these matters in the privacy of a one to one discussion with the interviewer, who she knew was a medical practitioner.

> *In my country talking about sex is like a taboo, and you don't just talk about sex like people do here. You can't just say in public...no even if, like, three, four people, you can't just be talking about sex, you know... people will be thinking you are crazy.*
>
> **M1H+female**

Engagement with other Africans in the UK

For some participants there was a desire to build relationships with other African people living in the local area; meeting with others from their home country it was felt, enabled a forum to talk about news and issues from home. For some, long hours at work and attempts to keep in contact with family at home precluded much time to socialise in the UK. Some of the participants spoke of their sense of isolation and contrasted this with the highly socialised way of living in Africa where everyone felt they were known and in turn knew many others in their circle.

> *But here you can live in a street alone and live there five years and your neighbours won't still know you.* **Za1Umale**

However, many of the participants either did not prioritise social engagement with other African people or more deliberately sought to avoid them. Robust criticism of other Africans was apparent in a number of the interviews, along with a stated desire to keep distance between the interviewee and others from their country of origin.

> *I try not to associate with Zimbabweans, because Zimbabweans are dangerous (laughing)... It's not dangerous as in violent, but they mind other people's businesses. If you're doing your*

progress, they're not happy, so they'll try by all means to bring you down... they discourage in other words. **Zi3H+female**

For this woman, as for some others, there was a reluctance to utilise the services of the voluntary agency in its attempt to bring HIV positive African people together for mutual support. Feeling unable to trust other people from their country of origin some feared that information about their HIV status would reach their families and communities at home. Specifically, it was felt that it was safer to find support from people from African countries other than their own.

5.4. Fear of disease and of others: stigma, risk perception and denial

Fear emerged as an overarching theme across the interviews with African participants. There was a strong association between the experience of HIV in Africa and subsequent fear of the disease, and a relationship between the stigmatised nature of the disease and fear of the response of other people.

5.4.1. Fear of disease and of death

AIDS fatalism and the fear of death

As discussed previously, the experience of HIV infection in Africa for many of these participants had often been one the inevitability of death following infection with HIV (see section 5.3.1). The association between HIV and death was a prominent and consistent feature that many participants reflected upon in some depth. It was suggested by some that the subject of death, and considering one's own mortality, was in itself difficult for many African people to confront and that this *'African mentality'* [K2H-male] was the backdrop against which HIV was regarded. Even so there was extensive discussion about the association between HIV and death in these interviews, with some participants using metaphorical dysphemisms to convey the strength of this perceived relationship.

So if you're told you're HIV, the next thing you're waiting for,

you're waiting to die. You're just a moving grave.

Zi3H+female

... somebody [with HIV] is a living corpse. **M1H+female**

... he was drinking poison, or we call it poison. **Zi8H+male**

Fear of the disease as an inevitable death sentence was augmented by the belief that death associated with HIV was particularly painful. Thus, even those who did not expect an immediate demise often had extensive fears.

> *I wouldn't say I was expecting immediate death, but I know the death is painful. I have seen people dying of HIV in hospitals back home... it is painful. I was really scared of that to be honest.*
>
> **Zi10H+female**

Many participants identified views of HIV as a death sentence to be a barrier to voluntary testing and it was felt that many African people living in the UK, without the benefit of engagement with HIV services and medical care, persisted in this view of HIV. One woman, for example, felt that fear associated with this belief was the greatest barrier to voluntary HIV testing for African people living in the UK.

> *The thing is they fear very much but it is because they don't understand. It is not because they are not ill or anything else and it is not because they know they are sick, it is because of fear. Most of them it's FEAR because they don't understand what it means. Many people understand if you are HIV you are finished and you are dead... like me that was my understanding before.*
>
> **K1H+female**

Most of those who knew they were infected with HIV gained reassurance from accessing medical care and particularly from being made aware of the benefits of treatment, which modified their initial fears about death's speedy inevitability. This group of participants often stressed that their understanding that HIV did not inevitably lead to death was primarily gained as a result of engagement with treatment and subsequent to their diagnosis. They commonly felt that most Africans in the UK did not share their understanding that antiretrovirals can help to control the course of disease and considerably prolong life.

> *... the impression they have is once they've got the virus, they are going to die - and very soon.* **Zi7H+male**

This was largely borne out in the interviews with participants who had not been tested for HIV, amongst whom there was only a single respondent who suggested that death from HIV infection was not inevitable.

Fear as a barrier to HIV testing

The majority of participants who had undergone HIV testing experienced it as highly anxiety inducing. Even those who had eventually learned that they did not carry the virus recollected the fear that they experienced at the time.

> *... the first time I did the HIV test, yeah, my heart was in my mouth ready to explode because I did not know what to expect.* **Ca1H-female**

The reaction to receiving news of being infected with the virus was often overwhelming, with powerful emotions of shock, anxiety and fear.

> *When I was told that I was positive. Oh gosh. I was just in shock really... it did affect me mentally. I was very anxious and I ended up on Diazepam. I behaved very funny.* **M1H+female**

Often, participants who had eventually been tested for HIV as a consequence of developing symptomatic disease had delayed seeking medical help because of their fear of HIV. Some of those who had not yet been tested for HIV had previously considered voluntary testing but, being afraid, had put off testing. One man, for example, had considered an HIV test because he and his girlfriend were hoping to have children, but admitted that each time they discussed it they did not follow through on their intentions.

> *I am scared because I've seen a lot of guys, girls dying... we keep on saying "Let's go" Then it just vanish all of a sudden. We just don't talk about it after..."OK, OK, fine. We'll do it this weekend." Or "We'll ring tomorrow." But then, again, you stop talking about it.* **S1Umale**

Knowledge of the benefits and availability of antiretroviral medications emerged as an extremely powerful influence on the perceived relationship between HIV

and death, and it was commonly believed that this knowledge could help to reduce anxieties around HIV testing. This is discussed more fully in section 5.6.1.

5.4.2. Stigma

Most participants raised the concept of stigma in relation to HIV and it was felt that it largely arose from the strong association between HIV and inevitable death. The stigmatised nature of HIV was in turn seen as a barrier to HIV testing. Thus, if the perceived link between HIV and death could be broken, it was suggested that HIV would be less stigmatised and more people would be willing to be tested for HIV.

> *Some people actually can't shake hands with you, they just try to avoid you... All they think is, "OK, that's HIV, that's death." No one wants to come near you. So I think once that has been dealt with and people with HIV feel welcome in the society, they might actually help other people to share and to volunteer to go and get the test.* **Zi7H+male**

Stigma and isolation

A powerful aspect of the stigma associated with HIV was the sense of isolation from others in society that arose when infected with HIV. This affected friendships and other close relationships, with some having been abandoned by their partner. Being known to be HIV positive was felt to have a dehumanising effect.

> *African people... don't really give each other some respect about it. They don't see you like a human being after you've told them that. They take you like real junk.* **Zi4H+female**

Participants commonly expressed their sense that people infected with HIV were alienated from society, being held at a distance from normal social interaction. This feeling was not limited to experience in Africa but was also the expectation and experience in the UK.

> *People won't touch you; they don't want to touch you with a long*

spoon. No, they won't want to touch you with a long spoon man. That's a fact. **Ni1Umale**

Stigma and 'promiscuity'

In the discourses around stigma, there was extensive discussion about the presumed association between HIV infection and 'promiscuous' sexual behaviour. Participants who had not been tested together with those who had a negative test result generally emphasized this link. Those known to be infected with HIV more often placed emphasis on it being a perception, and wished to stress that their sexual history was not one of multiple risky sexual partnerships.

I think the stigma really stems from the fact that people think you are promiscuous really. **Zi9H+male**

'Promiscuity' was consistently described in negative terms such as shame and immorality and the assumed link between 'promiscuity' and HIV infection was thought to act as a powerful disincentive to being tested for HIV. Some felt that the fear of being labelled an immoral person made it preferable to *'stay not knowing'* [Zi6H+female] whilst those who had been tested often did so in secret.

If I told them [friends] I was going to have an AIDS test, they would probably take me as very immoral and probably start seeing me as a strange person. **K2H-male**

HIV was seen as *'a dirty disease'* [Zi13H-male], which attracted both judgement and condemnation. Often a person with HIV would receive little sympathy or support because of a belief that they had brought it on themselves, and because it was largely understood to be sexually transmitted.

[The stigma] is still there; if I walked in a room and said I've just been diagnosed with breast cancer, everyone would get up and give me a hug, give me a kiss or [say],"I'm so sorry" and so on. If you got up and said you have HIV, I wonder how many people will get up and hug you. I think most people think you brought it on yourself. **Za2H+female**

Amongst those who had not been tested it was generally apparent that stigma remained a barrier to testing. Even when it was perceived that it might be

possible to live healthily with HIV, when a diagnosis of HIV was not seen as an automatic death sentence, the attitude of others was still a very negative influence. It might be better not to know.

> *It's a question of "how will people take me?" because everyone will change their attitude towards you, how they will look at you, how they will talk to you... You are still a person with AIDS, you can still live but I think it's not an easy thing to do... and it would be best maybe it's secret or I didn't know.* **Za1Umale**

5.4.3. Denial and the perception of risk

The interview accounts illuminated various ways in which participants viewed their own likelihood or risk of being infected with the HIV virus. It was particularly revealing to explore how people known to be carrying the virus had perceived their own risk status prior to receiving their diagnosis. It is remarkable how consistently most of this group had felt that they were unlikely to be infected.

Participants used a variety of conceptual frameworks as the starting point from which to view their own risk. Thus, for example, the prominent concept of 'promiscuity' as discussed previously (page 182) was a powerful 'benchmark' against which many attempted to assess their own level of risk.

The moral filter

It was common for participants to express a sense of certainty about not being infected because, in their own eyes, they had lived an upright and moral life. For example, one HIV infected woman had considered HIV testing irrelevant to her own situation precisely because she had not been 'promiscuous'. If her husband's AIDS related illness had not supervened she would not have proactively sought HIV testing.

> *If G had not become ill and gone into hospital, would you have considered an HIV test?* **Interviewer**
>
> *No! In my case, no I wouldn't. I wouldn't have because it's something you know is sexually transmitted, then if you know*

> *yourself I haven't been sleeping around in my life, so... I tell even my friends when I was growing up if we were sort of talking things I'd say, "If HIV is coming from heaven, then I'll be having it but if it's not from heaven, then that's not for me."*
>
> **Zi5H+female**

The 'moral filter' was likewise present for many other participants, and acted as a barrier to HIV testing. In some cases the response was extreme, as in the case of an African woman offered an HIV test as part of routine antenatal screening.

> *... so she was saying, "I cannot believe what they [the midwives] are telling me that I should have blood tested for HIV. Me? I'm a married woman!" That's what she said. "A married woman! And they think me I stand in the street?"...That's what people think that if you've got HIV it means that you stand in the street.*
>
> **M1H+female**

Knowledge and beliefs

Knowledge of disease and beliefs about supernatural and religious protection have previously been discussed (see pages 166 and 170). It is worth drawing attention again here to the impact that beliefs and knowledge have on the perception of individual risk. Thus for a person who believes in the supernatural protection of God, the reality of the risk their sexual activity has exposed them to is powerfully modified, with a commensurate impact upon the necessity they attach to being tested for HIV.

> *... they say, "I believe God cannot let me have it." Although they know that they have probably been having sex with more than two partners.* **K2H-male**

The health filter

When considering the likelihood of being infected with HIV participants generally took their current state of health into account. As discussed on page 167, there was often little awareness that HIV may have a relatively long asymptomatic stage. Thus, many of those who had never been tested and, prior to testing, many who subsequently tested positive for HIV had considered an HIV test unnecessary in the absence of what they perceived to be HIV related

symptoms. HIV testing was not seen as a screening test but rather its value was generally viewed through the filter of the individual's own state of health.

> *At that time I wanted to consider an HIV test, I just think myself "Oh, what for?" Because I just say to myself "I am healthy. It's not important." If you're walking and you're looking healthy; your weight seems fine, nice complexion.... (laughing). At least you can do this and that; very active. So there wasn't any reason for you to think you're positive but...* **Zi3H+female**

Although this woman, based on her own health assessment, did not feel it necessary to seek HIV testing proactively, she was subsequently found to be HIV positive as a result of routine antenatal testing. She reflected on how fortunate she had been to be tested.

> *I just say to myself,"Oh C [baby] is my saviour really" because if it wasn't for him I wouldn't have been tested. So I keep thinking he is my saviour more than anyone.* **Zi3H+female**

The distancing filter

Although there was generally a high level of awareness of the prevalence of HIV in Africa and of the high risk of transmission of HIV for those who had lived in Africa, often there was an attempt to distance oneself from this when considering risk at an individual level. Amongst those who had been tested for HIV this had frequently been a factor in delaying being tested. The prevalence of HIV in the community was compartmentalised as other people's problem, at some distance from the individual's own life and situation.

> *Most people know it's there but not in their lives. It's nothing to do with them. It's other people's problem, immoral people, people who have got social problems.* **Zi7H+male**

Denial

Denial emerged as a prominent theme, which was reflected both in discussions about perception of risk and in the recollections of immediate response to diagnosis. Denial was a powerful influence on those who had been at risk of infection, resulting in the setting aside of an intention to seek HIV testing.

You keep on hoping for the best even though you know you have been at risk. At the back of your mind you keep thinking, "Oh I have been at risk, maybe I could be lucky I'm negative"... Back home when I saw my friend dying of the disease I thought about it, but then I said, "I think I'm OK, let me just leave it."... at the time when I came here I was convinced I was negative.

Zi10H+female

Several participants mentioned the approach of 'hoping for the best'. Even participants who recognised that they had been at substantial risk of contracting HIV continued to deny the possibility. One participant, who had not been tested, reflected on his sexual history and recognised that he had been careless. Even so, he desired to turn away from the possibility, suggesting that he could not be hurt by what he did not know.

In Africa I was careless, I was careless. There are certain things that I even think about it today and think did I actually sleep with that person? ... When you are a photographer, you get a lot of challenges, so it was hard at that time. **S1Umale**

A lot of challenges? **Interviewer**

You meet a lot of girls who want you to take their photos for free so... Most people they just hope for the best, you know there's a saying that what you don't know doesn't hurt you.

S1Umale

In contrast to the widespread denial around the possibility of being infected, some participants spoke in terms of facing up to reality and of wanting to know their status. This was the minority view and was seen mainly in those participants who had proactively sought HIV testing, although some of those who had tested positive for HIV spoke with hindsight of the benefit of facing reality.

I always thought that I was exposed to it because when I was living with my husband he used to cheat on me ... in my mind I always thought maybe I was at risk. That's why I had to do the test because I really wanted to know and I had to prepare myself for anything. **Zi1H-female**

5.5. Opportunities for testing: how, why and when?

Participants were asked about their knowledge and use of medical services in general, and more specifically about how and where HIV testing can be accessed. Participants who had been tested for HIV in the UK were encouraged to describe the process and experiences involved, whilst those who had not accessed testing were asked how they might proceed if they chose to seek HIV testing. In their accounts many participants expressed the overarching struggle associated with decisions to be tested for HIV, the whole process often being seen as a psychological battle.

> *Oh God, it's not easy, it's not easy. It depends how your heart is, how your challenge is, but Oh God no! It's not easy!*
>
> **Na1H-female**

5.5.1. Access and structural barriers

Registration and appointments

The way in which health care is provided in the UK was thought to be confusing, especially in the early months after arrival in the UK and, for some it had meant delay in registering with a doctor. Some participants felt that the process of registering with a GP required a lot of effort. Sometimes it was difficult to register because certain practices were not accepting new patients. For one African woman who was pregnant this was a particularly difficult situation. Despite her attempts to register with a GP to enable monitoring of her known thyroid condition, it was relatively late in her pregnancy when she eventually accessed medical care. Diagnosis of her HIV infection status (and access to treatment) was therefore at a late stage of pregnancy.

Getting a timely appointment with a doctor was presented by a number of the participants as a difficult issue and for some it was implicated in the delay in obtaining a diagnosis and appropriate treatment. This applied both to appointments with GPs and the genitourinary medicine clinic. One Malawian

woman recounted the difficulty she had in getting to see her GP even when she was very sick, resulting in self-treatment for presumed malaria although it eventually transpired that her symptoms were related to HIV infection.

> *I did make an appointment with the GP but I was supposed to go there after 2 weeks. I suffered, "gosh this is just too much." So by that, I did take the malaria tablet called Fansidar.* **M1H+female**

Some of those who had been tested had been directed to the genitourinary medicine clinic rather than being offered the test directly at the GP practice. Accessing the services of the genitourinary medicine clinic proved consistently difficult, and waiting times for appointments for HIV testing through the genitourinary medicine clinic were seen as a real barrier to testing. It was difficult for participants to live with the anxiety of waiting to take an HIV test, once they had decided it was important for them to be tested. For some, the GP was seen as a way of accessing earlier testing, although this route was by no means taken by all.

> *I went there [GU clinic], but they say I should book an appointment and for that month they were fully booked until the next month... And I said: "Oh no, it's too long, I need to know." I was really anxious to know... and then I decided to go to my GP and he said, "It's all right, we can do it here".* **Zi2H-male**

The route to medical care

Ease of access to medical care was raised as an important issue because it was sometimes the case that there was little determination among participants requiring testing to follow through on their limited desire to test.

> *Okay, it's not something I'd want desperately, so I wouldn't put much effort, if I can't find it once I probably wouldn't look for it again, but the first place I will go to is a hospital or something, yeah.* **Za1Umale**

It was suggested by some that knowing where to go was the most important consideration in improving the uptake of HIV testing.

> *It's knowing where to go, knowing what to do when you feel, do I*

really have It? ... but honestly if you know where to go... that would be the greatest help that can be offered. **Za2H+female**

It emerged from some interviews that the likelihood of a person proactively seeking testing varied at different times, depending on the state of mind of the individual. It was suggested that in order to confront the possibility of being HIV positive, one needed to be feeling strong, and it was at these times that it was important to capitalise on the willingness and desire to know one's status. Thus, waiting for an appointment could be a major barrier, and uptake might be improved if it were possible to walk into a clinic and ask to be tested at a time when that person felt ready to do so.

Fright is a major factor here... but then I think everybody should be able to walk into a clinic and say "I feel good tonight - test me." That's my honest belief that everybody should be able to.
Ni1Umale

Immigration status and entitlement

As has been mentioned previously, immigration status may be a barrier to accessing care because of fear of being identified as living in the UK illegally. It was suggested that some African people would be unlikely to access any statutory service.

I know they are living here, they hide, they don't come out. They don't...they can't even face somebody like you, because they are here illegally. **K1H+female**

However, issues around immigration status in relation to entitlement to free NHS treatment were rarely raised during the interview discourses. It was not raised spontaneously by any participant in relation to HIV testing, and was discussed by only a small minority of those receiving treatment, although none had faced the situation of treatment being denied them.

5.5.2. The doctor patient relationship

The interviews explored participants' perceptions of health care professionals, both in primary and secondary care. The perceived quality of the relationship between doctor and patient varied enormously across the participants, with a considerable number recounting negative experiences that had undermined trust and confidence in their doctor. These accounts focused on issues relating to HIV testing but also included broader encounters with health professionals. These perceptions are of relevance to HIV testing because, when negative, they diminish the likelihood of future engagement with health services.

> *Someone would go to look for help but you know the treatment you get and the responses you get they might put you off and you decide, "What's the point?"* **Zi6H+female**

Confidence

Participants expressed mixed feelings about how much confidence they had in their doctor in general, and specifically how they viewed the competence of doctors in relation to HIV. These perceptions varied widely, both in relation to individual doctors and to clinical setting, whether primary or secondary care.

For example, some spoke with confidence about GPs' knowledge, and felt that they could rely on receiving the correct advice and information, sometimes specifically referring to HIV testing.

> *So I didn't know where to go, but instead I just knew if I go to the GP then automatically I will get the information.* **Zi1H-female**

Others were more critical, with several participants complaining about a perceived lack of engagement by their GP with their symptoms. It was a relatively common perception that a standard response by GPs is to prescribe painkillers, with the result that participants felt they were neither fully heard nor were their concerns taken seriously.

> *NHS doctors don't do no check up anyway. All they do is prescribe paracetamol and Panadol for you.* **Ni1Umale**

At the more extreme end of the spectrum of views, there was very little confidence in either primary or secondary care doctors. While poor regard for NHS doctors in general was a minority view, it was clear that a substantial number of participants had, on occasion, questioned the competence of individual doctors at specific points on their medical journey.

> *... half of the GPs don't know anything... you go to a hospital you expect somebody to be intelligent, somebody who knows something... there's not education enough within the service for them to know exactly what is treatable and what is not treatable.*
>
> **M2H+male**

Doctor power and control

The theme of doctor control was prominent in a number of interview accounts. Participants felt that the doctor directed the sequence of events and expected patients to comply. For example, blood tests, including HIV testing, were not presented as an option for discussion, but as a requirement.

> *[The GP] asked if I'd been tested when I was in Congo or when I came here. I say, "No" They say, "You must be tested."*
>
> **Co1H-male**

Similarly, participants felt that it was usually the doctor who decided on a course of action or treatment, with inadequate explanation about why this was necessary and lack of recognition of the patient's anxieties. One participant gave the example of receiving a telephone call from her GP in which she felt forced to comply with the doctor's wishes, despite her fears and lack of understanding of the reasons for the suggested course of action.

> *He said, "Could you please pick up your bag and meet me on [Hospital 1-ward] within an hour?" You know, working as a health care assistant, I've heard people talking about [Hospital 1-ward], saying it's for people with HIV and AIDS. I started shivering. I was so scared.* **Zi4H+female**

A strong feeling of anger towards their doctors emerged from some interview accounts. A substantial minority recalled consultations in which they felt their views had been dismissed, with the doctor's agenda being the driving force. A

recurring issue was the belief that participants were not being told all that there was to know, that they were being 'kept in the dark'. For example, several felt that doctors were withholding information relating to results of investigations. One woman spoke of her surprise at discovering that the referral she had been promised was actually for HIV testing at the genitourinary medicine clinic.

> *So appointment came and I was surprised that the address there was saying STD clinic in [Hospital 5]. Well I went there and the first leaflet I saw, it was like everybody who comes here should have their syphilis and HIV test and the Hepatitis test. So now, I was getting quite anxious because why did not she tell me what's all this about? ... But the thing which annoyed me a bit - I know she tried her best, really I do appreciate what she did - but the time she did refer me she didn't, I don't know whether she was scared to tell me about HIV thing... That's the only part, which I wasn't happy about it.* **M1H+female**

Feeling that the doctor knew more than they were revealing led to some participants feeling even more anxious. For some this was compounded by the terminology used by doctors. Even so, participants often showed understanding, making allowances for the seemingly inadequate communication. The participant above was generous in her gratitude and belief that the doctor was doing her best. Others participants suggested that their doctor's actions might have been an attempt to protect them from anxiety. Attempts to rationalise the behaviour of GPs may have arisen from participants' awareness that the interviewer was herself a GP. This issue will be discussed more fully in Chapter 6.

Trust and understanding

Being able to trust their doctor emerged as an important issue in many of the interview accounts. Notwithstanding the previous examples, many of the African participants felt that they could trust their doctor, and described a very good relationship with their GP in which they felt they could discuss any matter in confidence.

> *I know if I tell him my problem he won't go and tell someone*
> **Na1H-female**

In contrast to some of the more negative experiences, many participants spoke warmly of the relationship with health professionals and valued the support they had received.

> *So I just explained it to him, the situation. He was really good actually. He was really good.* **Zi3H+female**

Being understood and listened to was an important aspect of a good relationship. Many of those who had been diagnosed HIV positive spoke warmly of their interactions with nursing staff in particular, although this was not universally the case.

> *They are very supportive because they know this is a disease which is very stressful, and the nurses there are very good and they are sort of encouraging you, talking to you.* **Zi5H+female**

> *The nurses were horrible, they were! If I was late, 5 minutes for my appointment they wouldn't see me. Yeah, they were horrible, but the doctors were all right.* **Za2H+female**

The majority of participants had found at least some supportive health professionals who they could *'really open up to'* [Zi9H+male] and had encountered compassion in some of their relationships with doctors and nurses. Generally, participants who recounted bad experiences had subsequently found alternative, more supportive care.

Racism

Some participants raised the issue of race as a prominent feature, which profoundly affected how they felt they were perceived and treated by health professionals. One woman from Zimbabwe, for example, felt that her country of origin was a label that she carried, with insensitive discussions about her between medical staff, focussing on her race more than on her as a person.

> *The first question that Dr X asked me, was, "Have you been back home recently to Zimbabwe?" I said, "Yes." And then he looked to his colleague and then they shook their heads... I felt just because I was from Zimbabwe, Dr X, when he came with his*

> *colleagues, every morning when it's the doctors' round, one is like relating my history to the other doctors, junior doctors, students or whatever, who tell them that this is a 30-year-old girl from Zimbabwe. Recently she's been back from Zimbabwe, so, so, so, so, so.* **Zi4H+female**

For another Zimbabwean woman, the reportedly racist comments directed at her by her GP led to a complete break down in the relationship. Subsequently discovering she was infected with HIV she felt unable and unwilling to return to her GP, believing that she would not be treated well.

> *I actually got upset because he says to me, "Oh, these people from Zimbabwe" but he didn't elaborate what he wanted to say... It made me feel sort of being sectioned or being degraded, it was humiliating. Yeah, I didn't like it. Even up to now he doesn't know but maybe it's because I don't want him to know. I would rather look for another GP because I don't know how he would treat me if he gets to know that I am HIV positive.*
>
> **Zi10H+female**

Although such poor treatment was the experience of the minority of participants, with the extreme represented above, it was not an isolated experience.

> *... and if a GP cannot touch you, then they are in the wrong place...maybe it's a cultural thing as well. Maybe they don't like Black people, I don't know... this is here in UK. Yeah, so don't go around looking for the GPs I've met.* **M2H+male**

5.5.3. Symptoms, sickness and missed opportunities

The participants represent a wide range of experiences relating to the process and outcome of HIV testing, with some remaining untested for HIV at the time of interview. The majority of participants known to be infected with HIV eventually underwent testing as a result of illness, some at the instigation of and by the GP, some at the instigation of the GP through the genitourinary medicine clinic, some directly at the instigation of the genitourinary medicine clinic, and some as hospital inpatients having either been admitted by the GP or through the Emergency Department. Almost universally it emerged that there had been some delay in testing and missed opportunities for earlier HIV testing, with

consequent low CD4 count at diagnosis and for some, lengthy undiagnosed suffering and long hospital admission. A summary of the HIV testing process for each participant is shown in Appendix 4.

Whilst delayed diagnosis can, in part, be attributed to denial and lack of knowledge for example (see sections 5.3.1 and 5.4.3) many participants would have responded positively to timely discussion of HIV with health care professionals.

Missed opportunities

African participants known to be living with HIV were asked to recount the process by which their HIV status came to light. It emerged clearly from the majority of these accounts that participants had often been in contact with medical services, most frequently a GP, on a number of occasions in the months prior to their diagnosis. From several accounts it was evident that there had been repeated visits to the GP with substantial ill health that did not, apparently, alert the medical practitioner to the possibility of an underlying diagnosis of HIV infection until months had passed. In some instances the patient's illness became so severe as to necessitate hospital admission and it was later still before an HIV test was undertaken.

> *I was passing urine with blood all the time. It was for about five or six months. And I kept going [to the GP]. It was like I was going every other week if not every week with the pain.*
>
> **Zi6H+female**

Some participants felt that an opportunity for earlier testing was missed by their GP because they were given an incorrect diagnosis to account for their symptoms. For example, one participant was told that she had asthma and attended the surgery's asthma clinic regularly for a period of several months, despite her deteriorating symptoms of tiredness, coughing and loss of weight. Her condition declined for a period of months before the combination of being seen by a different GP and developing *'black marks all over my legs'* [Zi4H+female]

led to her admission to hospital and eventual diagnosis during three months of hospital stay.

Although not universally the case, most participants who had not been tested for HIV were also in contact with medical services. Thus, even though not attending with possible HIV related symptoms, for these people too there had been missed opportunities for HIV testing. Indeed, one participant had believed that 'routine blood tests' at the GP surgery had included a test for HIV, although it is unlikely that this was in fact the case, as the subject had not been discussed and there had been no consent given. Even so, having assumed that these tests meant that he was HIV negative, he stopped using condoms with his regular sexual partner.

Sickness and suffering

The missed opportunities for earlier HIV testing and diagnosis had an inevitable impact on those who suffered HIV related illness and yet remained undiagnosed. Despite repeated visits to seek medical help some participants continued to suffer pain and illness. Eventual lengthy hospital admissions might have been avoided or at least shortened and their illness might have taken a less severe toll on them if diagnosis had been earlier in the course of disease.

> *I think if I had it [the HIV test] sooner, I think I couldn't have gone maybe even in hospital... I think even maybe I wouldn't have even gone crazy (laughs).* **M1H+female**

Whilst the potential for avoidable suffering was most marked in those who were eventually discovered to be carrying HIV infection, it also emerged that missed opportunities for testing resulted in a degree of mental anguish for other participants too. Some felt that not having immediately available access to testing caused stress. It has previously been noted that participants referred to the need to 'grasp the moment' whilst they were feeling strong, but that access to HIV testing at the genitourinary medicine clinic was often difficult because of limited appointment availability (see page 187). Thus, it might be several months later, if at all, that HIV testing would be accessed. For example, one participant who had been at high risk of infection through multiple casual sexual partners in Africa

had asked his GP about HIV testing for himself and his girlfriend and had been directed to attend the genitourinary medicine clinic. Although he had been ready to be tested on the day he first discussed it with his GP, he remained untested by the time of the interview, which was three months later.

Determination and resolve

Commonly, those participants who had proactively sought HIV testing expressed their sense that determination had been an important feature, with the decision to test being described by some in terms of a battle or a struggle within themselves, which they eventually overcame.

> *I think this fighting within my heart had been going on for quite some time,"Get tested. Don't. Get tested. Don't. Go and see someone." You come to the point where you say, "That's it, I'll do it"* **Za2H+female**

In addition to resolve, some participants felt they had needed to be persistent in their encounters with their GPs. Persistence was a feature for some of those with undiagnosed illness, but also emerged in the accounts of those who received a negative HIV test result. One woman who had nursed her house mate and fellow asylum seeker through her AIDS related death described her fear of having been infected and what she felt to be a subsequent battle with her GP to access HIV testing.

> *First of all they refused, they didn't want...I insist, I was there every week and then the third week they accept to give me the tests.* **Ca1H-female**

On the other hand, where resolve faltered, the diagnosis and appropriate management of HIV infection was severely impeded. This is well illustrated by the account given by a Zimbabwean participant who had been suffering from general malaise for two years, during which time he had not followed through on his intent to register with a GP and access medical help. Following the onset of weakness and chest pains he had, on the advice of a friend, eventually attended the genitourinary medicine clinic. Although an HIV test had been taken

in July he had not returned to the clinic to be told his test result was positive until December, having put the issue out of his mind by attending parties and heavy drinking even though he had been unwell.

> *A doctor wouldn't be any help because I wasn't going to really concentrate on what I was saying to him. So I said, "Let me wait". I said to myself, "I will call them." I kept on saying, "I will call them, call them, call them" till Christmas Eve when I decided to contact them.*
> **Zi12H+male**

It emerged during the interview that he had spoken to no one of this news, and that he had subsequently not attended his hospital appointment for confirmatory tests and assessment. At the time of the interview (nine months after the initial HIV test) he was waiting for a further follow-up hospital appointment. Thus, without appropriate resolve, the necessary follow up and management may not be followed through.

Reflections with hindsight

Within the interviews with HIV-infected participants there were reflections, with hindsight, on the process of testing. Many recognised that their knowledge of the disease and available treatments had been altered by the engagement with medical services their HIV status had necessitated.

> *Maybe I'm saying now because you know I've been through it.*
> **Zi6H+female**

Participants who were HIV positive almost invariably held that they would have sought testing sooner if they had known what they now knew. Many expressed a desire to encourage others to seek earlier testing, and not to wait until they become unwell.

> *I'd honestly encourage them to get tested, because whether you do it now or later you still find out anyway because you'll get ill, so you'd rather do it now when you don't have any permanent damage to your health.*
> **Za2H+female**

Some of those who had sought medical advice, but for whom the diagnosis was delayed, felt that they had been let down by clinicians. It was implicit in their

reflections that they blamed their doctors, at least in part, for some of their suffering.

> *If they had pursued the tests then, I think the earlier the better. Because it took me six months still in pain here and there, so I was not well really those days.* **Zi6H+female**

On the other hand, some HIV positive participants had been identified through voluntary HIV testing offered as a result of routine practices, such as the antenatal screening process and partner testing. These had been diagnosed prior to the development of illness and expressed gratitude that they knew their status and could access treatment.

> *I think that was something like a blessing in disguise, because at least now I know I've got this disease, which needs these tablets.* **Zi5H+female**

5.6. Improving uptake: knowledge, targeted testing and the role of primary care

Previous sections of this chapter have considered the barriers to voluntary HIV testing that emerged from the African participant interviews. This section will draw together views of participants on ways in which some of these barriers might be overcome. The experience of many participants was one of late HIV testing and consequent prolonged illness and lengthy hospital admission. Others remained without having been tested, whilst some had sought HIV testing and been found not to be infected with HIV. The perspectives of these different groups were explored in relation to overcoming the barriers to testing they had faced or currently faced. Participants were asked both general questions about what might have helped them to earlier HIV testing, and specific questions relating to the possible role of primary care in improving the timely uptake of HIV testing.

5.6.1. Knowing the benefits

Participants felt that to encourage the uptake of HIV testing, and most especially prior to the onset of HIV related symptoms, it was crucial that African patients know the benefits of early diagnosis. The experience of HIV in Africa had commonly been that there was little, if any, advantage in early diagnosis (see section 5.3.1). The majority of HIV infected participants had received their diagnosis relatively late in the disease process with HIV testing prompted by ill health. They only knew the benefits of HIV testing after diagnosis, and it was commonly felt that earlier knowledge of benefits might have prompted earlier testing.

> *Maybe if you said to me, "Oh A, are you prepared to go for an HIV test because there are advantages A, B, C, D, E" I would have definitely gone for the test.* **Zi10H+female**

Participants who had proactively sought HIV testing cited a variety of benefits as having influenced their decision to undertake the test, whilst those who remained untested at the time of interview displayed less knowledge of the advantages associated with earlier diagnosis.

Treatment

Participants who were aware of the availability of antiretroviral medication consistently felt that treatment availability is a powerful incentive to timely HIV testing. Not all participants had knowledge of the existence of medications that modify the course of the disease process (see page 164). In some cases knowledge of treatment was gained during the interview and rapidly became an incentive to test. For example, one South African participant expressed surprise when it emerged during the course of the interview that medication existed that could alter the course of the disease, and this new knowledge made a substantial difference to his attitude to being tested for HIV.

> *I'm quite shocked. I never knew there was a treatment.* **S1Umale**
>
> *Does it help?* **Interviewer**

> *Oh yeah, it does because ... I believed that once you've got AIDS then you just wait to die, or they give you painkillers or whatever. I don't know any treatment and I haven't heard of any treatment... maybe 90% don't know there is treatment... [my girlfriend] no, her sister, no, her friend of her sister, no. They don't know there's a treatment that can slow it down no, no, no it's a definite no!* **S1Umale**

Across the range of interviews there was a strong feeling that the benefits afforded by treatment needed to be emphasized, along with the need for treatment to be started before the *'immune [system] has already been shattered'* [K2H-male]. Some participants felt that appropriate medication, started in a timely manner, had the advantage of avoiding complicating illnesses, the effects of some of which may be irreversible, as was the experience of a Zimbabwean participant who remained in hospital with cerebral lymphoma and CMV retinitis at the time of interview. Thus whilst having access to treatment following HIV testing was of real benefit, it was seen as especially important to emphasise that the greatest advantage is to be gained from early testing, prior to the onset of symptoms.

Planning for the future

Many participants felt that knowing one's HIV status enabled planning for the future. One student, who had tested negative, had in part been prompted to establish his HIV status because he believed that if he were infected the financial cost of his studies *'would not be worth it, to spend a fortune'* [K2H-male]. More commonly, participants felt it was beneficial to know their HIV status in order to ensure a more healthy lifestyle if they were infected with the virus. However, one participant expressed a strong contrary view, believing that when looking to the future it was preferable not to have a diagnosis of HIV hanging over him, until illness necessitated the need to know.

> *The moment you know it's a U-turn... You can't do anything, you can't eat, you can't sleep, you have no relationship, you don't want to go to work... So what's the benefit of putting somebody in that position unless they are sick?* **M2H+male**

A number of participants felt that there were particular benefits to HIV testing at the point of making a long-term commitment to a partner. It was commonly felt that before considering marriage it was advantageous for both partners to be tested.

> *If you intend to have a serious relationship, like getting married or trying to have a baby I think it's advisable for one to find out*
> **Zi7H+male**

Effecting change

An important consequence of undertaking HIV testing was the change in behaviour and lifestyle that ensued, both for those who were found to be carrying the infection and for those who were not. If infected, participants thought it valuable and possible to adjust diet, exercise and stress levels to live more healthily and consequently improve the prognosis.

Some participants felt that if a person knew they were HIV positive it would have benefit to others through the use of safer sex and limiting the spread of disease.

> *I think it is a good idea to know your status, how you are, so that if you have it you can prevent it to spread to the next person, so that you can take care of yourself better and eat good food so that you can keep healthy.* **Zi2H-male**

For those who had received a negative test result there was often a very real sense of relief. Some spoke of the psychological benefit of no longer having to live with uncertainty. Even those who found they were infected with the virus were sometimes relieved to know the facts and then be able to deal with the reality.

> *I know where I stand. I am HIV. It's not going to change. So what I think about now is looking after myself. I'm not worried about anything else now.* **Zi5H+female**

Whilst people who discovered they were HIV negative felt relief, they did not feel that this led to complacency or more risky sexual behaviour. On the contrary,

advice given as a result of post-test counselling was seen as useful in effecting behaviour change, especially as the prospect of repeating the process of HIV testing would not be taken lightly. Some recognised the presence of past risk-taking behaviour which might have resulted in contracting the virus, seeing a negative test result as fortuitous and an opportunity to avoid future risk.

> *It's like you have managed to cross a river of crocodiles, but don't attempt to cross yourself back again to the other side because you never know when the crocodiles will be awake (laughs)... Never, never think of crossing back simply because you have managed to cross it this time ... don't do anything that will find you on the wrong side.* **Zi13H-male**

Raising awareness

Participants often felt strongly that there was a publicity vacuum about the benefits of timely HIV testing. Several participants suggested music as an effective medium for communicating messages about the benefits of timely HIV testing. Others spoke of the lack of general advertising and advocated amongst other ideas, advertising on billboards and posters in doctors' surgeries. The television was cited by many as a powerful medium through which to communicate the benefits of testing to African people.

> *I think the best way that you can do it is to make a documentary on the telly. It's quite scary ... the majority of Africans are the one's who are HIV positive. So a documentary every now and then ... saying, "It's very difficult to realise that you're HIV positive, but something can be done before it's too late." I think it would be really helpful.* **Zi3H+female**

5.6.2. Targeting, compulsion and discrimination

Within each interview the subject of targeted HIV testing was discussed at some length. In cases where this topic did not emerge spontaneously from the participant, he or she was asked to express views and feelings about being offered a voluntary HIV test on the basis of having lived in Africa. These discussions were commonly linked to the participants' own experiences of HIV

in their country of origin and to their perceptions of the high prevalence of HIV in African countries as discussed in section 5.3.1.

Racism and discrimination

Perceptions of racism were raised by many of the participants in relation to HIV. The impact of perceived racism upon the doctor-patient relationship has already been discussed (see page 193). Even if they had not personally experienced racism, participants commonly felt that racist media portrayals of African people as health tourists and as sources of infection pervaded societal attitudes and acted as a barrier to HIV testing. Discussions about targeted voluntary HIV testing therefore explicitly explored perceptions of discrimination and racism. Generally it was felt that the advantages of timely HIV testing for African people made the offer of such a test acceptable.

> *I can't feel bad because the one who is telling me to do test is helping me because if I know I am HIV positive, the earlier I know the earlier I get treatment. So it can't be difficult or bad to ask me such a question.* **K1H+female**

The offer of a test based on country of origin was also acceptable to those who had not, at the time of interview, undertaken an HIV test and it was felt that it would encourage testing.

> *Yeah, I wouldn't even hesitate... I wouldn't look at it [as racist] because if anything, it's concern and I'd know my status ... There is no other place which is as bad as Africa when it comes to medical issues and health, so it wouldn't even cross my mind.* **Za1Umale**

Whilst, several participants acknowledged that some African people might not feel entirely comfortable with an offer of testing that was linked to their country of origin, only a small minority felt that targeted voluntary testing was unacceptable on the grounds of perceived racism. When explored further, the participants who held this view tended to accept the general premise of increased risk associated with Africa but recognised that even faced with such facts, a 'gut reaction' might be one of offence.

> *It's a fact, it's a real factual thing that is really truthful... but it would be a bit offending in a way to say, "You are from Zimbabwe..." Of course, the fact is true. You know it's just like "You are ugly." I know I am ugly, but if you were told by somebody "You are ugly" it offends you (laughs). That's the real thing, that's the truth that is there. But someone doesn't want to listen to the truth, that's the real thing.* **Zi13H-male**

Overall, the African participants in this series of interviews were clearly in favour of offering voluntary HIV testing to African people in a targeted way and in contrast to the above participant, there were even calls for a bullish approach.

> *It's not at all [racist]. Anyway it's a fact that people from Africa are the majority [of] the HIV positive and everybody knows [that] and you know, it's really high time that people should realise something must be done.* **Zi3H+female**

Communication and information

Good communication emerged as a prominent concept across the range of interviews and was seen as key to overcoming possible feelings of discrimination in relation to targeted voluntary HIV testing. Participants stressed the importance of how the subject was introduced, discussed and positioned. Particular emphasis was placed upon the need for the health professional to communicate that their motivation was the patient's best interests.

> *The approach is very important. If a GP approach the person and tell him not only because he come from Africa but we want to keep everyone healthy, we want to do HIV testing so that when we are treating you we can know what we are treating, I think it is good... We just want the people from Africa who are living in this country to be healthy because they are here.* **K1H+female**

Consultation style and the doctor patient relationship were considered to be important aspects of effective communication. It was felt, for example, that if an African patient felt relaxed with their doctor they would be much more likely to consider the offer of an HIV test made to them by their doctor.

> *Some doctors when they're talking to you they're like serious, they look straight into your eyes, like what Chris Tarrant does on "Who wants to be a millionaire" and if the doctor said it in such a*

way, I would definitely say no, but you know if they say it in a more relaxed way, just a general talk... Like I say, it's the approach; the way it is said. The way it is said is really to me really important. **Zi3H+female**

Providing impetus

There was widespread recognition that many African people *'need a push, people need to be reminded that this is important'* [Zi1H-female]. Participants felt that being offered an HIV test opportunistically might encourage earlier HIV testing and avoid late presentation of disease. Particularly in situations where self perceived risk was low, it was felt unlikely that an African patient would proactively seek HIV testing.

So if a GP has got someone who is coming from a country which has got high risk of HIV, I think it is a good thing because... like in my case I was saying I will never ever get tested, only if it [HIV] was coming from heaven. So someone like me will be saying the same thing, not knowing. **Zi5H+female**

Some participants who had never tested for HIV felt they would be more likely to seek a test if they had cause to think about HIV. Even giving general information about HIV within a clinical consultation was seen to have a potentially beneficial effect. One Zimbabwean respondent drew a parallel with the interview experience, which he felt had influenced him.

So what would encourage you to think about getting tested? **Interviewer**

I should think, encouragement...I mean it's like talking, just like what we are doing right now. It like brings it to the forefront of your mind to say,"Hey, I never thought of that, I'd better start thinking about it and get myself tested, yeah." **Zi11Umale**

Choice and compulsion

There was extensive discourse on issues around choice and compulsion and these issues mainly arose spontaneously during discussions around targeted HIV testing. To varying degrees, five participants called for compulsory HIV testing

for people whose country of origin is in Africa. Three of these called for compulsory testing at port of entry, whilst stipulating that it should not be used as a basis for allowing a person into the country. It was further suggested by one of these participants, that port of entry testing should be extended to include British citizens who had stayed in a country with high HIV prevalence for more than a certain length of time. Compulsory HIV testing in pregnancy was advocated by one participant whilst another put a case for performing an initial HIV test on African people without their specific knowledge or consent. However, more generally participants placed great emphasis upon the need for patient choice. Most respondents felt that the acceptability of targeted HIV testing was incumbent upon it remaining a voluntary procedure.

> *I think if a GP explain to someone, "There's a problem in your country, in Africa, of this disease, why don't you think about it? It's not I'm forcing you but why don't you consider having a test because that will save your life"* **Zi5H+female**

It was generally accepted that some African people might decline to be tested for HIV even if clear information had been communicated in an appropriate way. However, respecting the patient's choice remained important in the view of many, with some feeling that an initial refusal might not be the final outcome of the consultation.

> *... tell him, "You see that map? You come from this region. This region is of a higher risk. Would you be willing to take a test?" and then if he says no, you just give him lots of pamphlets telling him what is HIV, how it can be treated, how it is good to know earlier than going there late. ...he would probably get the point and come to you later as an individual case.* **K2H-male**

Overcoming 'HIV exceptionalism'

Although it was clear from many of the accounts that the diagnosis of HIV continues to present particular challenges, it is interesting to note that some participants attempted to normalise the infection. They drew a parallel between the higher prevalence of HIV in Africa and that of certain other diseases such as Hepatitis B infection and sickle cell disease. For these participants, their response

to being offered an HIV test of the basis of their country of origin was shaped by their previous experiences with these other diseases.

> *That would have been OK, yes, even when I wanted my Hepatitis B jab vaccination he said to me, "Oh you come from Zimbabwe, you might have been exposed to this Hepatitis B so I will take a sample of your blood to see if you have been exposed" That didn't offend me. They did the test, and then he said ""No, you've not been exposed." Then I was vaccinated.* **Zi10H+female**

Similarly, one participant had previously been identified as a sickle cell carrier and felt that the higher risk of HIV that African people had been exposed to should be seen in similar way.

> *To me, I don't find it offensive. It's just like the sickle cell anaemia. Like I say, people from Africa, you are more prone to have it because of where you came from. So I'm not offended by that.* **Zi3H+female**

5.6.3. The role of primary care

Much of the discussion about the acceptability of targeted HIV testing was set in the context of primary care, and to some extent the case for primary care's role has already been established. However, it emerged that the participants' experiences of GPs had been mixed and thus their views on the role of GPs and their staff in the process of HIV testing were probed more fully. Clinical practice varied across the range of GPs encountered by these participants, with some undertaking HIV testing in their surgeries, some preferring to refer the patient to the genitourinary medicine clinic to be tested and some apparently not engaging with possible HIV disease at all. Even so, where there had been experience of perceived poor care it was commonly the case that an alternative GP had been seen and on the whole, participants were satisfied with the relationship with their GP.

The suitability of primary care as a testing site

Despite the difficult route to HIV testing that some participants had experienced, with a number of examples of perceived poor treatment having been cited (see

section 5.5) it was widely held that primary care is a suitable place for the HIV testing needs of African people to be addressed. In principle, notwithstanding examples of seemingly inadequate practice, participants were keen to see GPs discussing HIV with their patients and giving appropriate information and advice. Indeed, some participants felt that GPs were ideally suited to this task because of their accessibility and profile.

> *Everyone knows about GPs. When you're feeling unwell you go to see the GP. I think if GPs were the initial... even if they didn't do the testing, you mention it to the GP, the GP directs you to a place where to go, or they can do the testing.* **Za2H+female**

The extent to which participants felt it was appropriate for their GP to be involved in ongoing HIV care after diagnosis varied considerably. Some of those who had not been tested, or who knew they were HIV negative, assumed that the management of HIV would largely take place within primary care. On the whole, these participants expressed considerable confidence in the competence of GPs in relation to HIV.

> *GPs give you the way forward [they] tell you, "This is the status, the way forward now is to live like this, your type of food you are supposed to be eating is like this. This will keep you healthy. There are dos, and don'ts and just abide to those." (sighs). Maybe we will be the first ones to die, us the healthy ones and others will still be alive (laughs).* **Zi13H-male**

There was more consistency across the interviews regarding the actual delivery of the HIV test. Although a few felt that it would be acceptable for the initial discussion to take place within primary care and the testing to take place elsewhere, the great majority felt that the both the pre-test discussion and the HIV test should be provided seamlessly, with practice-based testing being available in each GP surgery.

> *I think if I was sure to get tested at the [GP surgery], I think it would have been much better than me going all over the place, like sending me to STD clinic. I really, I really, really was annoyed.* **M1H+female**

Publicity and confidentiality

The issue of confidentiality was widely raised, with participants feeling that it was extremely important that the results of their test would not be known by anyone other than their doctor or people they chose to tell. It was felt that reassurance was needed in order to encourage African people to undertake HIV testing.

> *I think people are afraid of the confidentiality... if their test comes, saying that this person is HIV positive, they think maybe it will be known by everybody.... People need to be told that it's confidential and nobody else has to know about it. It's only between you and your doctor.* **Zi1H-female**

Some participants felt that a GP's surgery is a good place both to advertise the availability of testing and to provide reassurance regarding confidentiality. The use of maps highlighting high prevalence areas of the world and posters providing information about the benefits of early testing would be appropriate in waiting rooms and clinic rooms of doctors' surgeries. At the same time it was felt that it could be made clear that the results of any test undertaken would remain confidential.

> *If they made it confidential and advertised it... surely anyone who walks into the surgery can read it's there and we do also offer you know HIV like pregnancy test, they advertise on TV ...blue line you're ok, red whatever, pink, something like that. If they advertise something like that, and you go to the GPs, they say, well we'll do it in confidence, you don't have to worry about confidentiality, I think most people would come forward to do it.* **Za2H+female**

HIV testing for newly registered patients

The majority of participants were registered with a GP and within each interview the process of registration and seeing a doctor or nurse for the first time was discussed. Some participants spontaneously referred to these new patient consultations as an opportunity for African patients to access HIV testing. It was

felt by some that being offered an HIV screening test along with other routine urine and blood pressure checks might make testing an easier prospect.

> *I think the first time you register with a GP, that's the best time to say, "Look while you are here, would you like maybe to..." Because normally when you go to the GP, I used to have urine tests and some other specimen. I think that's the best time when you're just registering with the GP, to say, "Hang on, if you're from this country, can we do this test as well."* **M1H+female**

It is noteworthy that a similar, spontaneous suggestion was made by one African participant who at the time of interview had not undertaken HIV testing.

> *When you go and register with a GP, it's like they will test you for sugar diabetes, like taking your urine sample. If you could also ask, as a GP, "I've got to know your status. I'm checking for your diabetes in you, I might as well check for AIDS" ... there's no way I could have said, "No I don't want I" so if by then I was tested that could have been one year, eight months earlier than now.* **Zi11Umale**

Where participants did not spontaneously raise the subject of new patient registration as an opportunity to improve the uptake of HIV testing, they were specifically asked for their views. Most felt it was a good idea and volunteered that they would have been likely to agree to an HIV test if it had been offered at such at time, with appropriate explanation and choice. The new patient check was thought to be an ideal time to screen for HIV because whilst patients often register while feeling well, they are unlikely to attend for a further consultation unless they are sick.

> *... because most people wouldn't be willing to just to go if they are not unwell, because you only go to see a doctor when you're unwell. When you are OK you just don't want to know really.* **Zi6H+female**

A small minority of patients were reticent about new patient HIV testing. It was suggested that it might be preferable for a GP to raise the subject with an African patient at a later time, once a relationship of trust had been established.

> *:... it's like now I know [my GP], she knows me, we can talk, I can talk anything that I want. I have got that confidence in my*

> *GP because that relationship has come. So it's like as time goes on, things will be able to be discussed... but on first instance, just coming in, that's my first time to see you and you introduce that to me, already that gives me that inferiority complex.*
>
> **Zi13H-male**

However, on further reflection the participant above felt there was a time advantage to offering an HIV test at the initial consultation, recognising that there might be considerable delay before the next consultation. As long as there was good communication and the patient retained autonomy, it was felt that the advantages outweighed the disadvantages.

> *The problem is how later is later? Maybe the client won't come back until after six months... It's OK, let us introduce it there and then ... if things need to be done, let's call a spade a spade, that is that and it depends what the client either accepts or not - up to you.*
>
> **Zi13H-male**

5.7. Concluding comments

This chapter has presented the main themes around HIV testing that emerged from the interviews with African participants. African people from a range of sub-Saharan African countries and with a variety of personal, family and educational backgrounds participated in the interviews. In particular, the interviews included African people with a range of experiences of HIV related care in the UK; people who had been tested for HIV and knew that they were infected with the virus, those who had been tested and knew they were not infected as well as a number of African people who had not been tested for HIV and were therefore unaware of their HIV status. Many of those known to be living with HIV infection had discovered their status at a relatively late stage of disease, as the result of illness and possibly avoidable hospital admission.

The complexity of life and the struggle to manage the competing priorities of work, accommodation, finances and immigration status for example were a prominent factor in the timing of access to health care and to HIV testing in particular. Thus, for these African people, barriers to timely HIV testing are not

isolated from the other demands and challenges they face in their daily lives but are set within and modified by the context in which they live as migrants in the UK.

Whilst the present challenges of living as a migrant in the UK influenced the uptake of voluntary HIV testing, so too did past experience of HIV in their country of origin. Negative experiences of HIV in Africa profoundly influenced understanding of, and feelings about, HIV for these participants. Fear and fatalism relating to HIV was a prominent theme across the range of interviews. Whilst a prominent feature in all accounts, many of those who were receiving HIV related care reflected on how fear of the disease had been modified by greater knowledge of antiretroviral treatment. Indeed, complete lack of knowledge of disease modifying drugs emerged as a modifiable barrier to HIV testing in some of those who had not accessed HIV testing.

The ongoing influence of Africa extended beyond knowledge and experience of HIV. Cultural and spiritual beliefs continued to exert a powerful influence on many of the participants, with HIV testing and health care in general being understood within an often complex construct that incorporated beliefs that were often sustained by continuing contact with family in their home country.

Opportunities for improving the uptake of timely HIV testing by African people have been outlined. From the interviews it emerged that offering targeted voluntary HIV testing to African people based on their country of origin was broadly acceptable. As long as the benefits of early HIV testing are communicated well, and provided that patient choice is respected, participants generally felt that the offer of HIV testing would be well received. Further, it emerged that primary care was seen as a suitable setting for HIV testing to be carried out and with certain provisos, HIV testing linked to new patient registrations in general practice provided an ideal opportunity to overcome some of the barriers for African people.

The next chapter will provide further interpretation of the key findings from this series of African participant interviews together with interpretation of the results

of the interviews with professionals. It will consider the findings in the light of the published literature, provide further reflections upon the methodology of the study and consider possible implications for policy and practice.

CHAPTER 6. DISCUSSION

6.1. Introduction

The aim of this study was to consider potential opportunities to improve the uptake of voluntary HIV testing in UK African communities by exploring the factors that lie behind late and undiagnosed HIV infection in this group. The study has focused on African communities outside of London; in recent years increasing numbers of African people have settled outside of the capital and the prevalence of undiagnosed infection in African people is higher outside London. It has considered the perspectives both of professionals and Africans living in the city of Bristol and findings from interviews with each of these two groups have been presented in Chapters 4 and 5.

The purpose of the current chapter is to draw together, compare and discuss the two sets of findings, interpreting them in the light of the literature and identifying the key common issues to emerge from the study as a whole. It will also consider the relationships and tensions between the two data sets.

The research process as a whole will then be considered with reflections on the methodology and methods adopted. The quality of the research will be evaluated, including an assessment of its strengths and limitations, and issues of reflexivity will be noted.

Finally, the chapter will consider the possible implications of the findings for policy, clinical practice and further research.

6.2. Key findings and their relationship to the literature

Before considering the key findings from the study as a whole, it is important to make some more general comments about the relationship between the two sets of data.

6.2.1. The relationship between the two sets of interviews

An important aspect of the current research was the attempt to explore issues around HIV testing from the perspectives of different individuals involved in this process. Undertaking an HIV test is not done in isolation by African people but involves the professionals who provide the service. For this reason both professionals and African participants were included in the study in order to gain as full a picture as possible of the HIV testing process for African people.

This appears to be the first qualitative study to include a range of professionals involved in HIV care of Africans in the UK and therefore the first time attention has been paid to the level of emotional engagement professionals feel with their patients, their own vulnerability in the relationship, and the strength of feeling and sense of injustice expressed.

Professionals, as is apparent from their accounts in Chapter 3, were not dispassionate or uninvolved in the drama. Rather, their accounts were often emotionally driven and grounded in personal experience of relationship and involvement with African people. Thus, although the interviews with professionals served partly to 'set the scene' they were not purely objective and factual accounts. The data presented in this thesis demonstrate the importance of their personal attitudes and values; professionals were more than mere suppliers of information. Their interpretations of the issues involved were necessarily shaped by their personal feelings, which in turn were influenced by their engagement with African people.

Similarly, some of the accounts from African participants were shaped by their encounters with health professionals and other specialists in HIV testing and care. For example, participants who were known to be infected with HIV were generally in contact with a variety of professionals and these relationships influenced, to at least some extent, the way they approached their diagnosis and in turn their views on HIV testing.

It is perhaps important to note that at least some of the participants in each group were known to each other. The sample of professionals was deliberately selected to include the key people involved in the delivery of HIV services in Bristol and therefore included many of the clinicians currently delivering care. The 'circle' of professionals involved in HIV care in Bristol is reasonably small, and professionals participating in the study were therefore likely to know each other. One of the challenges of conducting this research outside of London was the care that needed to be taken in reporting the data to minimise the identifiability of participants. It also followed that HIV infected African people were receiving care from a small pool of professionals. Although for reasons of confidentiality the names of clinicians were removed from interview transcripts, a number of African participants made direct reference to the care they had received from clinicians who the researcher had previously interviewed. It is also worth noting therefore, that although professionals tended to stress their commitment to and concern for African people, the experiences of individuals who had actually been under their care were not always consistent with this.

The themes emerging from the professional and African interviews were closely linked. Whilst partly arising from the interview chronology, it also reflects the attempts made by professionals to understand the worldview of African people, with this desire apparently borne out in empathy, support and not uncommonly an attempt to advocate on their behalf. However, as many of the professionals recognised, their understanding of their African patients is often partial and limited by a western medical perspective. Whilst acknowledging that, for example, African spirituality, health beliefs and culture all exert an influence upon African people and impact upon the HIV testing process, the nature of these beliefs and the ways in which they exert their influence were often poorly understood by professionals and served as a source of frustration to them.

In terms of chronology, for the most part the interviews with professionals preceded those with African participants. This allowed the issues raised by professionals to be brought into the subsequent discussions with Africans to

explore directly some of the perceptions of professionals regarding the needs and beliefs of African people. This was instructive in highlighting the agreements and disparities between professionals and their African patients and the particular issues around which differences had not been fully appreciated or misconceptions had arisen.

The specific tensions and areas of agreement between the two sets of findings will be explored further below in the discussion of the key findings that emerged from the study as a whole.

6.2.2. Discussion of key findings

The impact of late diagnosis and numerical increase

This study provides corroboration for the widely reported increase in the number of newly diagnosed HIV infections in black Africans in the UK.[9;66;282] Professionals in this study remarked upon the dramatic impact of the increasing number of HIV diagnoses in African people upon their own work over recent years.

Since HIV infection was first identified in the UK, most HIV prevention, care and research activities have been focused in London and there has been little research into the HIV prevention and care needs of Africans living in settings where community groups and services are less well established.[24] Yet in recent years African people have settled outside of the capital in increasing numbers, partly as a result of the government's policy of 'dispersal'. This study has contributed to understanding the impact of the increasing burden of HIV disease in Africans settling outside London by exploring the pressures on services and the professionals who provide them in the city of Bristol. It points to the increasing pressure upon HIV treatment services and drug budgets in a city with a population of 380,000, which has witnessed an increase of 60% in its black and minority ethnic population between 1991 and 2001.[25]

The increasing burden of HIV infection in African people impacts not only upon the individuals who are infected but also upon those who provide care for them, and this study has highlighted not only the increased workload but also the emotional burden on professionals involved in their care. Findings from this study begin to bridge the gap that has existed in understanding the needs of service providers who are charged with providing HIV prevention and care services for increasing numbers of African people in settings outside of London.[24;125;128]

Much of the body of research about HIV and African communities in Britain has been quantitative and has highlighted both the increasing number of infected individuals and the tendency for Africans to present later in the disease than their white counterparts.[10;13] The literature suggests that some hospital admissions amongst those diagnosed late in the course of infection might have been avoidable and draws attention to the financial cost of this to the NHS.[138;189;196;196] However, whilst there is recognition of the detrimental impact of late presentation on individuals as a result of potentially reduced effectiveness of antiretroviral medication,[6] there has been little emphasis upon the effects on individual African people from their own experience and viewpoint. This thesis contributes to a broader understanding of the impact of late diagnosis of HIV by examining the personal accounts of African patients who have been affected by late diagnosis; hearing the stories of extended hospital admission and lengthy illness, and highlighting the psychological and physical cost of avoidable morbidity.

Being an African and a migrant: the contribution of context

A number of studies have highlighted the multiple challenges and hardships faced by many African people who have migrated to the UK and in particular that those living with HIV often face their diagnosis on a background of uncertain immigration status and financial insecurity.[125;137;144;157] This thesis has examined the relationship between multiple competing priorities and the delay

in accessing HIV testing services. For many African people, life is complex and issues arising from economics, employment, family, housing and immigration status all compete with health care for attention.

Anderson and Doyal found that many HIV-infected African women living in London had past experience of stressful life events.[144] The present study of men and women confirms that many African people had a background of profoundly traumatic life events including rape, incarceration and violence against themselves and their families. Further, the strain of having left family at home and, for some, anxiety regarding their safety, was an ongoing feature of life. For all these reasons African participants in this study often did not prioritise their health, sometimes not seeking medical care until symptoms became prominent and interfered with daily life.

Much of the literature in the area of HIV has focused on black Africans as if they were a homogenous group, whereas this population is diverse with many communities of varied ethnic identities, cultural practices, languages and religions.[166] However, whilst it is undoubtedly true that there is heterogeneity within UK African communities, this study found that a number of common issues were consistently raised by African people across a range of countries of origin. Indeed, many participants expressed a clear sense of 'African' identity; often participants from a variety of countries spoke of 'people from Africa', and made generalisations about the continent. Although there is a danger of oversimplification in presenting the findings as though they arise from a homogenous group, there appear to be enough stable properties to warrant considering an 'African perspective' where appropriate.

Professionals recognised that there are some common issues for African people, and that HIV prevention and care services must be sensitive to these needs. According to professionals it is inappropriate to attempt to translate services originally established for gay men to African people. It may be also be inappropriate to adopt models used with Africans in London to settings outside

the capital.[22;24] The findings of this study suggest that the experience of being an African migrant in the setting of Bristol might be different to that in London given that communities were less well established, with more limited community support and possibly a greater sense of isolation. Arising from concern for their African patients who face difficult and often multiple challenges and recognising the lack of community support in Bristol, professionals in this study aimed to show compassion and concern, attempting to be flexible and supportive including sometimes assuming an advocacy role.

This thesis has confirmed the findings of other studies that African beliefs and culture exert a powerful influence on African people in the UK.[124;167] It develops these findings by examining in more detail their relationship with perceptions and experiences of testing for HIV. Many of the African participants maintained regular contact with family and friends in their home country, often by telephone and email, with the effect of reinforcing belief systems established in the country of origin. Thus, beliefs about traditional medicines and for some, spiritual beliefs relating to witchcraft, continued to influence attitudes to health and health seeking behaviour.[169] Cultural norms around sexual activity, the aversion to condom use and the difficulty faced by women in negotiating safer sex were all apparent.[166;167;195] Professionals recognised that there were aspects of African beliefs and culture that they did not always adequately understand and that could present problems in their relationship with African people. In particular, even experienced sexual health clinicians found difficulty in discussing sex with African clients and sometimes struggled to understand their worldview and their health beliefs, with some deliberately attempting to 'Westernise' their African patients.

This study supports findings in other recent studies of African people living in the UK regarding the importance of religious, most often Christian, beliefs.[124;144;158;159] Belief in God was cited as an important source of strength and the church played an important social role in the lives of many. However, there was some suggestion that faith might act as a barrier to HIV testing for some if

they held an unswerving belief in the protective power of God or saw seeking treatment as evidence of lack of faith in God to heal. Corporate faith and church community were often not as important as sources of comfort and support as personal faith and prayer, confirming existing findings that HIV-infected individuals were often reluctant to disclose their status to their church communities.[157;161]

One of the most profound ways in which being African impacted upon attitudes to and likelihood of undertaking voluntary HIV testing was the past experience of HIV in Africa. Without exception, all of the African participants had personal experience of the devastating effect of HIV infection upon family and friends in their home country in a setting were medical care and access to antiretrovirals was, at best, limited. Recalling these experiences had a powerful negative influence on the volition to voluntary testing for many, so that only their own ill health would be an eventual driver for testing.

This study provides evidence to suggest that limited knowledge of medication that can modify the progression of HIV infection may be hampering the uptake of voluntary HIV amongst Africans in the UK. Contrary to the claims of an often hostile media that migrants from Africa are 'health tourists' whose intention is to seek NHS treatment,[155] this study found that many African participants did not appear to know much about the benefits of HIV treatments. Much of the knowledge of antiretroviral treatments was gained after diagnosis of HIV infection and some of those who remained untested were unaware of the availability of treatment. However, African people who had chosen to be tested and were found to be clear of the virus were mainly well informed about treatment availability. This may be important because it is this group of people who, by definition, undertook testing without having developed HIV-related symptoms. With the exception of one HIV infected participant who was diagnosed through antenatal screening and one as the result of 'partner tracing', others who had been tested for HIV and been found to be positive had done so relatively late in the course of the disease as a result of symptom development.

To encourage testing prior to symptom development, the findings of this study suggest that greater awareness of the benefits of treatment may be beneficial, thereby reversing the sense of hopelessness associated with HIV infection that arises from experiences of the disease in Africa.

Fear as an overarching theme

Fear was the most pervasive theme to emerge from this study, being central to perceptions of HIV and testing. Many of the barriers to HIV testing among Africans relate to fear of the disease itself, especially a belief in the inevitability of imminent death, a finding that is mirrored in other research.[157;181] However, the fear expressed by African participants, and recognised by professionals, was broader than the profound fear arising both from the disease itself and the anticipated reactions of other people because of the stigma attached to HIV and AIDS. For many African people, much of life was marked by fear and anxiety: fear of possible deportation and a related fear of official services; fear for family in potential danger in their home country; fear for those on medication that they may face a future without medication if returned to their country of origin; anxieties about finances, jobs and accommodation; fear for their children; and fear of discrimination and racism.

Some professionals elucidated their own fears, in particular recognising their discomfort in dealing with people whose beliefs and culture they felt they inadequately understood. There was anxiety for the well being of their patients and, for some whose training and experience was less extensive, anxieties related to the management of HIV itself. In particular, it emerged that for some professionals there was a fear of being perceived as racist that translated into caution in the relationships with their African patients, and their willingness to invite Africans to be tested for HIV.

HIV is highly stigmatised in UK African communities and the negative impact of stigma has been reported by a number of authors.[137;144;187] This study has developed these findings by examining perceptions of stigma in relation to

decisions and processes around testing for HIV. Many African people who undertake an HIV test are understandably anxious about the process and outcome yet few will find help or support from friends or family at this time. Even being known to take an HIV test is potentially stigmatising because of the strong association of HIV with 'promiscuous' sexual behaviour. Thus many do not disclose that they are undertaking testing, thereby being denied potential support of family and friends at a time of heightened anxiety.

The impact of perceived stigma upon disclosure was underlined in this study by the high proportion of participants who had not disclosed their status to more than one or two people beyond their health care providers. At its extreme, one participant had kept a provisional diagnosis of HIV infection entirely to himself for a number of months and had not even returned to clinic for confirmatory HIV testing or ongoing management, disclosing his provisional diagnosis within the interview, presumably feeling it was a safe environment in which to express his fears.

Perceptions of risk

For an individual to decide to seek HIV testing they first need to appreciate either a change in their health status (in which case the disease is already likely to be relatively advanced) or a transmission risk. The way in which individual African people perceive their risk of being infected is often much more complex than a construct in which the level of risk is directly related to the number of sexual partners and episodes of unprotected sexual intercourse. Corroborating the findings of other studies that indicate Africans who are HIV positive have a low self perceived risk, this research found that African participants who were carrying the infection commonly did not expect their diagnosis and were often profoundly shocked by their HIV test result.[157;181;195] The findings of this study go beyond those of previous research by identifying a number of risk 'filters' that appear to be used by African people in assessing their own likelihood of being infected.

There is some research evidence to suggest that uptake of voluntary HIV testing by Africans is increased in association with a past diagnosis of a sexually transmitted infection or with having an HIV-infected partner, whilst in one study it was found not to be associated with high risk sexual practices.[167;195;196] Health professionals in the current study reported an often-substantial mismatch between their assessment of transmission risk and the patient's self-perceived risk. This finding was borne out by the African participants; many of those living with diagnosed HIV infection confirmed that whilst they had not thought themselves to be infected prior to receiving the test result, with hindsight they acknowledged that there had been sexual activity that had exposed them to risk of transmission.

Self-perception of transmission risk by African people is therefore likely to be a significant obstacle to voluntary HIV testing if that testing relies upon a request coming from the individual concerned. It follows that improving the uptake of voluntary HIV testing may require health professionals to offer it more routinely and proactively.

The doctor patient relationship

The perceptions of African participants regarding medical services and their relationships with medical practitioners varied widely, and this is consistent with the differing findings of a number of studies.[140;144;165] A number of participants in the current study felt that their medical care had sometimes been inadequate, and there were occasional reports of their needs having been met with hostility and discrimination, serving to undermine trust and confidence in their doctor. Criticisms were levelled at both primary and secondary care practitioners and variously directed towards medical and nursing staff. Particularly strong feelings were expressed in relation to health professionals who did not share decision-making or give full information. African patients wanted their doctor to be open with them, to share information and to treat them with respect.

However, these criticisms were not universal and the majority of African participants had found at least some supportive health care professionals on their medical journey. Indeed, it emerged that finding an alternative professional, for example seeing a different GP, often resulted in a very different experience. Not all doctors were thought to have the same attitudes or knowledge and there was often relief at subsequently finding an alternative doctor.

Whilst some professionals recognised the need to maintain a certain level of professional distance, many of those working with African people in the provision of HIV services felt protective towards their patients, even advocating on their behalf or defying hospital rules in order to ensure they received appropriate care. Although this study suggests that professionals working in the field of HIV are emotionally engaged with their patients, expressing compassion and concern, there might be mismatches between the way professionals see themselves and the way in which African people sometimes understand their actions. However, notwithstanding the negative experiences, there was a great deal of good will on both sides. Although professionals expressed some frustration, this was often tempered by attempts to understand the difficulties faced by many African people. Whilst many Africans recounted negative experiences, most appreciated the care they received and felt they could trust their doctor.

However, it is important to recognise that all participants in this study, professionals and Africans, knew that the interviewer was a GP and it is quite possible that this influenced the extent to which criticism was levelled. For example, some criticisms of GPs within both sets of interviews were followed by an attempt to excuse or at least understand the behaviour. (For a fuller discussion of these issues see 'Reflexivity' on page 234).

Missed opportunities and willingness to test

A number of studies have suggested that for many African people who present at a late stage of HIV disease there were missed opportunities for earlier

testing.[111;138;283] This thesis confirms and extends these findings by exploring the reasons behind late diagnosis and, importantly, examines the opportunities for earlier testing that may have been missed.

Almost all African participants were in contact with medical services, with most having registered with and visited a GP, sometimes on many occasions. However, although they recognised the value of medical care in general and had accessed GP services for other conditions both chronic and acute, HIV testing was not high on the agenda of most African people until they became unwell with symptomatic disease. An important new finding to emerge from this study is that most African participants would have been willing to be tested for HIV if a test had been offered and the benefits of testing had been explained. Conversely, proactively seeking HIV testing, especially if it meant negotiating a pathway to a genitourinary medicine service that had problems with access and service provision, was unlikely to happen.

Some of those who subsequently became ill, and most especially where the delay in testing resulted in prolonged sickness and hospital admission, reflected that if they had been able to access appropriate treatment sooner, their hospital admission would probably have been avoided.

This appears to be the first in depth study amongst UK African people to explore issues around HIV testing with both those who have, and have not, been tested. Participants included those whose test confirmed HIV infection (often at a late stage of the disease), those who had not been tested and some participants whose test confirmed they were not infected with the virus. For the first time it has been possible to explore the reasons behind testing and its timing in these different groups, and to examine the motivations of those who undertook testing without being driven to do so because of HIV related symptoms. Understanding the motivations of those who were not forced by such events to seek testing might provide useful insight into how to promote voluntary HIV testing. This study highlights that knowledge of the benefits of testing and in particular knowledge

of the availability of antiretroviral medication that modifies the disease process is an important factor in an individual making a decision to discover their HIV status. It is notable that the participants in this study who proactively sought HIV testing without having developed symptoms of disease were generally more knowledgeable about HIV and treatment options, and less likely to see possible infection as a death sentence.

Perspectives on primary care and the role of non-specialists

This study corroborates other research in finding that primary care services are accessed by the majority of African people, and develops these findings by exploring in more detail the relationship that African people have with primary care.[165;181]

A number of studies have reported that only a small proportion of all HIV tests are undertaken in primary care.[17;112] The current study has explored the suitability and acceptability of primary care as a setting for HIV testing, finding that African participants believed GPs to be well placed to discuss HIV and to offer HIV testing, with many participants keen to see GPs giving information and advice. There may be issues to be addressed in relation to training (see section 6.4.2), especially in the light of some reportedly inadequate care. The findings of this study suggest that some delay in HIV testing may be accounted for by lack of symptom awareness by GPs, with HIV related presentations not always being recognised. However, on the whole African people felt that practice-based testing should be available in every GP surgery.

Specialists in the provision of HIV care were generally supportive of more HIV testing being undertaken in primary care and were willing to provide appropriate support and advice where necessary. However, whilst it has been claimed by some authors that advances in HIV treatment and care negate the need for HIV testing to be afforded special status, this study found an element of ongoing HIV exceptionalism, most notably seen in the attitudes of the specialist sexual health care advisor respondents.[19] These participants continued to desire

that HIV testing remained within the overall control of the genitourinary medicine service. It is possible that this arose in part from a desire to maintain their privileged status as 'experts', with their assumed specialist knowledge of the sub-population of HIV-infected African people authenticating their role.

The background of economic and social deprivation and precarious immigration status faced by many Africans in the UK may mean that there are more pressing needs than actively seeking out testing.[125] This study not only provides evidence to support this claim but also affirms the hypothesis that on this background there may be a role for increased primary care involvement in promoting early HIV testing; rather than waiting for HIV-related symptoms or greater awareness to drive proactive testing by African people, the GP is well placed to raise the subject as part of routine care.[181;284]

The majority of African participants in this study were registered with, and had accessed, general practice services, suggesting that primary care provides an opportunity to provide HIV testing services to the entire community, including African men and people without children. This finding is supported by evidence from a study of Ugandans living in London, which found rates of use of primary care services were similar for men and women and unrelated to whether people had children.[165]

Targeted testing based on country of origin

To deal with high numbers of undiagnosed HIV infection and late presentation of disease there have been many calls for improved uptake of voluntary HIV testing, with African people being identified as a particular focus for targeted work.[15;136] Either explicitly or implicitly these injunctions require that groups to be targeted will be identified on the basis of their country of origin. An approach that identifies people in this way will need to be sensitively handled in order to avoid further discrimination and alienation of migrant communities.

This study appears to be the first to examine the perceptions of African people to being the focus of targeted voluntary HIV testing. An important contribution of this study is the finding that whilst some professionals perceived that targeted voluntary testing based on country of origin may not be acceptable to African people, this was not borne out by African people themselves. Whilst some professionals felt uncomfortable with the notion, being particularly anxious about being seen as racist, voluntary HIV testing based on country of origin was broadly acceptable to African people. For African participants the most important determinants of acceptability were good communication and a clear explanation of the benefits of testing for HIV at an early stage, particularly being made aware of the treatment benefits afforded by antiretroviral medication.

6.3. Reflections on the methodology and methods

The purpose of this section is to reflect upon the methodology and methods used in this research and the overall study quality. The role of the researcher as research 'instrument'[220] will also be considered, as qualitative approaches typically recognise that the researcher's communication with participants is a part of knowledge production, and the subjectivities both of the researcher and of those being studied are part of the research process.[229]

6.3.1. Addressing quality in qualitative research

Firstly, some reflections on the quality of this research will be considered, with reference to debates about quality in the qualitative methods literature. In recent years there has been increasing concern with assessing quality in qualitative research, resulting in a proliferation of guidelines and criteria.[202;218;285-287] These concerns are part of a much larger epistemological debate about the nature and status of knowledge produced through qualitative research.[287;288] Those who take a purely relativist stance do not feel it necessary to account for the rigour of qualitative research because they claim there is no single reality to be known, while others argue that there is a need for evidence of rigour as the social world

does have some stable properties and that attempts should be made to confirm these properties.[214;218] Hammersley argues that whether there should be concern for truth or falsity depends on how the data are to be used. If the aim is to understand or explain social phenomena and the perspectives held by actors then there is no need for judgements of validity. However, if accounts are to be used as a source of information about the phenomena to which they refer, then researchers must be concerned with the 'truth' of the account.[218] The current study both explores the perspectives held by actors and considers the accounts as sources of information, and is therefore concerned with issues of 'truth'.

There are a variety of positions on whether qualitative research should be concerned with notions of reliability and validity that traditionally belong to quantitative research. Kirk and Miller define reliability as '*the degree to which the finding is independent of the accidental circumstances of the research*' and validity as '*the degree to which the finding is interpreted in the correct way*', asserting that these basic concepts apply equally well to qualitative and quantitative work.[274] However, Lincoln and Guba claim that different terminology and criteria for judgement of quality are needed because qualitative research is based upon a set of beliefs distinct from those of positivism.[269] The current study adopts the position taken by Lincoln, who calls for assessment of the 'trustworthiness' of qualitative research, which should include appeals to credibility and confirmability.[289] Each of these will be dealt with in turn.

Firstly, credibility refers to the 'truth value' of the data collected. To claim credibility the multiple constructions held by the informants must be represented adequately and these 'reconstructions' must be credible to the original informants (equivalent to internal validity). By obtaining the respondents' reactions to the analysis through 'respondent validation'[214] or 'member checking',[269] it is claimed that informants will be able to confirm the accuracy and validity of the study, clarify points, and add additional information to confirm the model further, thus enhancing credibility or validity.[269] However, Hammersley criticises those who define credibility in terms of respondent

validation as appealing to naïve realism.[218] He claims that because there are multiple realities, validity should not be defined in terms of whether informants judge an account to be true. There may be many reasons why a respondent may or may not admit particular aspects. For example, individuals themselves may not be aware of the entire range of influential factors in their lives, or the findings may be in conflict with the informant's self image and therefore, the inclusion of unflattering portrayals or details may not be approved of. The use of informants to validate findings also acts to ignore the social character of the relationship between researcher and informant, implying that it is the informant who has privileged access to the truth.[218] Fielding and Fielding also resist the notion that informants have privileged status as commentators on their actions:

> *'such feedback cannot be taken as direct validation or refutation of the observer's inferences. Rather such process of so called "validation" should be treated as yet another source of data and insight'.*[290]

In the current study, the researcher did not seek to validate the credibility of the findings by returning to informants with results from the analysis for 'member checking'. As outlined above, the assumptions behind such an approach are questionable. Further, there were substantial pragmatic reasons for not doing so; returning to such a hard to access and mobile group of respondents would have been extremely resource intensive.

Aside from 'member checking' another potential strategy to safeguard credibility is to 'triangulate' data collection by obtaining evidence on the topic from as diverse and independent a range of sources as possible.[207;240;285] Proponents of this strategy claim that by cross-checking observations amongst divergent data sources, apparent differences may eventually resolve themselves and a favoured interpretation is constructed that fits with all the divergent data sources. However, Silverman argues that the use of triangulation assumes there is one true state of affairs and whilst triangulation seeks to overcome context specific boundaries, it is not helpful to conceive of one over-arching reality.[214]

Hammersley and Atkinson claim that it is naïvely optimistic to assume that '*the aggregation of data from different sources will unproblematically add up to produce a more complete picture*'.[220]

Accepting these arguments, the current study did not set out to uncover one 'over-arching reality' but rather to explore issues from different perspectives and contexts, using both in-depth interviews and participant observation in a number of different settings. For example, interviews were conducted with key informants from a range of professional backgrounds, whilst in-depth interviews with African people included participants with known and unknown HIV status, from a range of countries. The two sets of interview data enabled the same broad issues to be explored from multiple perspectives. Whilst there was some divergence in perspectives on a number of issues, a degree of convergence regarding the key issues lends weight to claims for data credibility.

We have considered questions of credibility. The second aspect of trustworthiness is what Lincoln and Guba term 'confirmability'.[269] This refers to the trustworthiness of the interpretations drawn from the data. One of the proposed methods for checking the confirmability of the analysis is if a second researcher considers the data and agreement is reached on the emergent categories.[214;269;285] This 'reliability check'[214;285] aims to ensure that the emphasis is not on the investigator but on the data themselves. The second researcher should be thoroughly versed in the study and the issues being researched. They are then able to check whether the findings are grounded in the data, the appropriateness of the category labels, the quality of the interpretations and the possibilities of alternatives.[269] Strategies to check confirmability were incorporated within the current study. My advisors read the early interview transcripts and recommended the development of certain areas of questioning. One advisor independently coded two transcripts from the interviews with professionals and two African participant interviews, and provided more detailed scrutiny of the coding process. We compared codes assigned to transcripts by going through the transcript line by line, a process that revealed a notable level of consensus in

coding. She also scrutinised the descriptive accounts for each of these transcripts and examined whether the quotes provided for each of the codes related to that particular code. During this 'investigator triangulation' any discrepancies were discussed and resolved, usually by reference to the original transcript.[251]

In general terms, Mays and Pope claim that the basic strategy to ensure rigour in qualitative research is 'systematic and self conscious research design, data collection, interpretation and communication'.[285] Being 'self conscious' in the conduct of research enables the researcher to acknowledge her own background and beliefs and to reflect upon ways in which possible 'bias' might be introduced.[203] Thus, it is argued that reflexivity is an important aspect of ensuring the quality of the study.[291]

6.3.2. Reflexivity

The interview is a complex social encounter in which there is inevitably interaction between the researcher as research 'instrument' and the data because, as Hammersley points out, 'there is no way in which we can escape the social world in order to study it'.[220;292] [257] Thus, the researcher's own preconceptions should be considered as honestly as possible and it must be recognised that the people studied may have, at least in part, altered their behaviour for the researcher.[220] It is important therefore at each stage of data collection and analysis to maintain an awareness of the contextual details of the interview, for example its setting, and the interaction between the interviewer and respondent.[269] This 'reflexivity' is an important safeguard against a collapse of the interpretive process in which the researcher perceives only a mirror image of her own preconceptions.[292] It is argued that qualitative research can be most valuable when the researcher is able to use her own creativity within this reflexivity, to engage with the 'creative core of the research process', applying both intellect and imagination to the demanding process of interpreting qualitative data.[292]

The researcher cannot eliminate her own views and preconceptions, but she can reflect on these and make them explicit within the research account to make them permeable, so that the reader may have insight into how these may have shaped her interpretation of the data.[220;274] Reflexivity is essential in all qualitative research, but may be even more important in research involving ethnic minorities when researcher and researched are of different ethnicities.[250] Thus, in the current research, detailed contemporaneous field notes containing reflections on the interview dynamics, and how the interviewer's background might have shaped the accounts produced, have been a critical aspect at every stage.

Reflecting on the interviews with professionals

Difficulties can arise when conducting interviews with 'experts' if there is a power differential between researcher and informant. Powerful individuals might be concerned with their image and reputation, and as a result may question the motives and credibility of the researcher.[293]

During interviews with key informants the researcher took care to build rapport and to avoid appearing either over-deferential or critical of current service provision in the nature of the questions raised.[220] In the case of one respondent in particular, it became clear that the fact that the research was being undertaken at all was perceived as a threat to current policy. There was potential for this respondent to present the 'official' view and fail to engage fully and honestly with the interview process. However, sensitivity and reassurance regarding confidentiality eventually yielded real insight, for example into her own sense of discomfort with the policies she felt she was required to adopt in her professional role. For some informants, particularly those working in the field of social care, there was initially some hesitancy around engaging in research relating to a vulnerable group of individuals. Before, and to some extent during the interviews, the researcher was aware that she and her motives were being assessed before any depth of engagement was possible. It is likely that her role as

a GP influenced the interview process and what was discussed. It has been noted that when both interviewee and researcher are clinicians, interviews may be broader in scope, providing richer and more personal accounts because respondents are more willing to permit themselves a degree of vulnerability that reflects *'their perception that they are in 'professional' company'*.[255]

Dexter notes the teacher-pupil relationship inherent within some interviews with experts, where the 'investigator is willing, and often eager to let the interviewee teach him what the problem, the situation, is'.[294] In the interviews with professionals in this study this dimension was apparent in some, but by no means all of the interviews. Indeed, interviews with non-medical professionals on occasion presented an opposite challenge with the informants appearing deferential to the interviewer's own assumed expertise and asking their own questions. Britten asserts that the problem with this is that in answering these questions, clinical researchers may undo earlier efforts not to impose their own concepts and beliefs.[257] The various power relations had to be resolved during the process of conducting interviews by establishing the value of the research (and on some occasions the credibility of the researcher), building rapport within the interview and incorporating flexibility into the interview design.

Reflecting on the interviews with African participants

The research interview is a special form of conversation and a particular, even 'unnatural', social encounter in which there is an inevitable tension between achieving the goals of the research and developing an empathic relationship.[263;295] Many migrants have a feeling of alienation and mistrust towards health professionals, making it imperative that the researcher works in a way that is acceptable to this 'difficult to reach community' in order to generate rich qualitative data *'that illuminates the complex relational nature of sexual decision-making'*.[28]

Miller and Glassner claim that knowledge of the social world emerges from the achievement of inter-subjective depth and mutual understanding, which are in

turn dependent upon building rapport.[228] Some claim that building rapport is the researcher's paramount task.[296] The key elements of building rapport are establishing trust, showing genuine interest, assuring confidentiality and avoiding judgemental attitudes.[228] Together with ensuring a safe environment for the respondent to speak freely, and treating respondents in an ethical and non-exploitative way, the researcher recognised the particular importance of building rapport when researching a sensitive subject. It is through a *'close and trusting relationship'* that sensitive topics such as HIV can be explored.[244] Within each interview with an African participant, in a relatively short time the interviewer attempted to take the interaction beyond merely polite conversation and

> *.... establish an atmosphere in which the subject feels safe enough to talk freely about his or her feelings. This involves a delicate balance between cognitive knowledge seeking and the ethical aspects of emotional human interaction'.*[254]

However, as Giddens has noted, even during a transient conversation between two people, there is a relationship of power that each brings to the situation.[215] Whereas in key informant interviews the power dynamics may operate in favour of the respondent, in interviews with vulnerable patient groups the dynamics may be more likely to operate in the other direction, that is, in favour of the researcher. However, as Ribbens points out, issues of power are not limited to the interaction between researcher and participant but should also be seen on a much larger canvas.

> *Outsiders initiate research to translate others' social lives in terms that are considered relevant by a different audience. And this audience is frequently (though not always) a more powerful one.*[295]

In most qualitative interviews, the researcher is more familiar with the procedure of the interview and has greater control over the situation. The research interview situation is often new and unfamiliar for respondents, in which they may feel unequal.[232] Reflection upon potential power differentials within the African interviews in this study has particular pertinence because of the

professional role of the researcher as a medical practitioner. All qualitative researchers need to reflect on how interviewees perceive them and how any disparities in background or situation may potentially distance them from the interviewee within the interview. In the context of this study, this was most noticeable in terms of the interviewer's other role of medical practitioner. All participants knew that the interviewer was also a doctor, and this may have given rise to socially desirable responses in their 'public accounts', especially relating to questions about their health and health behaviour.[257]

When there is a difference in ethnicity between the researcher and interviewee there are additional factors that need to be given consideration. As Hammersley and Atkinson point out, *'race is, of course, not merely a matter of physical characteristics, but relates to culture, power and personal style'*.[220] In the current study a white European researcher was eliciting the views and experiences of black African participants. The 'insider' or 'outsider' issue described by Merton, regarding the extent to which rapport can be achieved in qualitative research, can have particular resonance where ethnicity is involved.[297] The extreme 'insider' position posits that only researchers who share the same background as their informants can accurately interpret their experiences. Commonality between the researcher and the informant has, in some research, been said to yield richer information.[298] At the other extreme, only those who do not share the characteristics of their informants can be sufficiently detached to form an objective view - a more positivistic stance in which the researcher aims to take a neutral, uninvolved view because of the difference in ethnicity.[250]

Given the heterogeneity of the African participants in this project in terms of culture, belief and country of origin for example, adopting an insider approach would have required almost as many researchers as participants. It is recognised that in this study there was not much commonality, in terms of personal characteristics, between researcher and African respondents. Their backgrounds, experiences, and for some, their medical diagnosis, were outside of the researcher's realm of experience and she was aware of being 'other' than the

researched. Some writers have suggested that not being socially close to interviewees has particular value. Rather than social similarity, what is required is sensitivity to the ways in which particular social characteristics may affect the research relationship and how they might impact upon the balance of power.[295;299] Rhodes, a white researcher, claimed that people made comments to her about racism that they would have assumed to be taken for granted by a black researcher.[300] White researchers may usefully emphasise their role as 'naïve researcher', wishing to learn about the informant's experiences, and respondents may be more likely to explain details of cultural issues if they assume the researcher does not have knowledge of group norms or values.[250]

In the current study, the researcher was aware of being given privileged access into the worldview of African participants. There were occasions when, in an almost conspiratorial vein, respondents gave accounts of behaviours and attitudes that were critical of their own culture. This was particularly noticeable concerning issues of disclosure and trust within African communities. The researcher heard on several occasions that the participant felt more comfortable speaking about HIV to someone outside of their own cultural setting, a setting in which discussion of HIV and sexual activity is difficult and often taboo. This finding corroborated the views of some of the key informants who had been approached in the early stages of study design to explore the appropriateness of the interview methods, who suggested that Africans would be willing to discuss HIV with a white researcher within a qualitative interview situation.

In a number of ways the African participant interviews were demanding. The interviews were sensitive not only because of the nature of the topic itself, but because they often triggered an emotional response, not only in the respondent but in the interviewer.[261] Generally, interviewees shared their experiences at a deep level, and in a number of the interviews the researcher heard accounts of painful past life experiences and current struggles. The unfolding narratives of life history, or at least key events, were often emotional and accompanied by tears. The researcher was not a passive observer at these times and was not

detached from her own emotions. To some extent this may have been therapeutic for the respondent as, perhaps for the first time, they felt they were being heard.[244] The researcher was particularly aware that this might be the case for some respondents who had not disclosed their HIV status to friends or family. A particular example merits attention: the case of a Zimbabwean man who had not previously discussed his HIV test results. He had been encouraged to participate in the research by a Zimbabwean friend and had been recruited in the belief that his HIV status was unknown. As the interview progressed it eventually emerged that he had taken an initial HIV test several months previously, and that this test had been positive for HIV antibodies. However, he had not attended for a confirmatory test or for consideration of treatment and had not revealed his probable HIV status to anyone else. Thus he was completely isolated in his knowledge and was, at the time of interview, suffering from general malaise and great anxiety. Although initially the interview was highly emotionally charged and required handling with great sensitivity, being able to acknowledge the situation and express his fears appeared to be both therapeutic and helpful in his journey towards acceptance and willingness to access appropriate health care.

In this and other interviews it was important to acknowledge the distress of the participant and to ensure they were willing to continue with or without a break. After the interview, care was taken to ensure that the participant had recovered before leaving, recognising the vulnerability and distress that the level of disclosure had evoked.[244] The researcher is a general practitioner and has experience in dealing with people who expose their emotional vulnerabilities. Some have suggested that the nature of general practice gives GPs a natural affinity and ability as qualitative researchers, with many of the skills held by clinicians being transferable.[206;257] Even so, the extent and nature of the discussions in some of the interviews had a profound effect upon the interviewer and this needed to be recognised and reflected upon. The use of copious field notes helped the researcher to process her own reactions. Additionally, on one

occasion, recognising the extent of the emotional impact upon herself, the researcher sought out one of her advisors in order to 'de-brief'.[244]

In qualitative interviews there may be a tendency for some respondents to ask questions of the researcher during the interview.[257] In the interviews with Africans this happened occasionally, mostly in the form of questions of a medical nature. The researcher attempted where possible to defer these questions until the end of the interview, in order not to undo earlier efforts not to impose her own concepts and be drawn into a 'doctor-patient' encounter. In some cases, it was necessary to direct the respondent back to their own physician for further advice. However, where appropriate, the researcher gave general advice when it was within her competence.

During the interviews the researcher was aware of her own background as a clinician, and where the conversation covered issues around symptoms and or diagnosis, she avoided probing inappropriately, being aware that the research interview is distinct from a medical consultation. However, there were some occasions when the researcher was unable to distance herself from her medical role, believing it would be unethical to do so. Two particular examples stand out. The first occurred when a respondent disclosed her suicidal ideation and depressive symptoms. The researcher felt she had a duty of care to this individual and intentionally explored this area further after the recording equipment had been turned off. The other most notable occasion was when there had been a very recent decision by a respondent to stop taking antiretroviral medication. This decision had clearly distressed the interviewee, who was confused and anxious following a sermon at her church in which her pastor had apparently claimed that taking medication reflected a lack of faith. The researcher felt that it was appropriate to explore this further after the formal part of the interview was over.

The interviews took place in a number of different settings and these settings had, to a greater or lesser extent, an effect upon the dynamics of the interview.

The researcher was very aware of the disparity in economic and social status between herself and the respondents, and this was underlined when entering the homes of participants who lived in hostels or bed-sits in some of the poorer areas of Bristol. In some situations, interviewer safety was a potential concern and she was careful to ensure that a university colleague knew where she was and was awaiting a phone call to confirm that the interview was complete and the researcher was safe.[266] On the whole, interviews that took place in the respondent's home were preferable in terms of putting the interviewee at ease early on in the interview and enabling them to keep more control of the process. One interview was conducted in the public environment of a public house but this setting made it more difficult to discuss sensitive issues and to maintain concentration and the researcher avoided similar settings for subsequent interviews.

Reflecting on the study as a whole: strengths and limitations

It is commonly recognised that there are many methodological difficulties relating to sexual behavioural research amongst migrant African communities in the UK.[28] Unemployment, poverty, long working hours, homelessness and family dispersal are among some of the difficulties faced by African communities, making engagement in sexual health research a low priority for the individual.[167] In addition, in many African communities sex and sexual matters are 'taboo' subjects and there are potential difficulties in discussing sexual matters in public. For all these reasons, gaining in-depth qualitative data on this sensitive topic within a 'difficult to reach community' requires that research be undertaken in a way that is acceptable to the community.[28] Despite these acknowledged difficulties, this study has been able to address an important, previously under explored and sensitive subject in a difficult to access group of people.

Most of the existing literature on HIV in UK African communities has largely been based in the capital and much of the research has been quantitative in nature. Qualitative methodology is well suited to the study of complex attitudes

and behaviours and is particularly beneficial in researching social phenomena which are intensely personal, sensitive and sometimes illicit as in this study.[201]

A major strength of this study is its inclusion of a diverse range of participants, both professionals and Africans. African communities are a very diverse and heterogeneous group with differences in nationality, cultures and migration histories. In its purposively selected sample this study has included African people from a number of countries, of both genders and from a variety of sources, sampling also those of known and unknown HIV status.

This breadth of inclusivity, according to Lewis and Ritchie, can support a claim to 'representational generalisability' - that is, its findings can reasonably be generalised to the parent population of African people resident in Bristol.[291] Moreover, presenting sufficient details of the original data and the contexts in which they occurred enables the degree of congruence between the research setting and other similar but not identical settings to be assessed in order to judge the transferability of findings (inferential generalisability).[291] Thus, whilst the current study was conducted in the city of Bristol, the transferability of findings to other settings with increasing numbers of HIV infected Africans presenting late to medical services can be considered.

The sample does, however, have limitations. Although vigorous attempts were made to recruit people from a range of backgrounds, and the sample included some who were not in contact with services and whose immigration status was at best uncertain, it is likely that certain sectors of the African population in Bristol remained hidden. It is possible that the reimbursement of £20 to participants biased the sample of those willing to participate. It is also possible that the sample disproportionately represented those who were more open to talk about sexual matters. Reassuringly though, once an initial contact had been made with an individual and the study explained in detail, there was high level of follow through on completing the interview. Only two potential participants were eventually dropped from the sample because of repeated failure to attend an interview at the agreed time and place.

It is also possible that the sample over-represented Africans with a higher level of education. Whilst it was not an inclusion criterion for participants to have a good command of the English language, interpreters were not used in any of the interviews, even though provision had been made for the use of interpreters if required. It is possible that African people who were less well educated, especially those who were less confident in their use of English, were more reluctant to engage in the research. However, it emerged from a number of interviews that participants felt that the population of migrants from Africa was itself weighted towards those of higher educational attainment, these people being more likely to have access to the necessary funds to leave their home country.

Social differences between the researcher and African respondents may have influenced responses as noted previously. However, the researcher's own experience of living in Africa gave her valuable insight into the worldview of African participants and this was particularly helpful in enabling her to probe more fully during discourses around culture and beliefs. Her background also assisted in building rapport with participants; during her two and a half years living in a rural part of East Africa she had established close friendships with a number of Africans, and these have been maintained and renewed during subsequent visits.

It is possible that participants' public accounts may have been selective and excluded that which might have been considered unacceptable to a health professional. Participants were aware that the researcher was a doctor and discussion may have been biased towards medical concepts. However, the wide-ranging nature of most accounts, including narratives that were critical of health professionals, suggests that to a large extent, these potential difficulties were overcome. Confidentiality was stressed at the outset and in a number of interviews sensitive and emotionally distressing ground was covered, suggesting that there was sufficient trust and good rapport established to enable participants to feel safe enough to express themselves fully.

The researcher's role as a practising general practitioner and the ways in which this influenced the dynamics of interviews with both professional and African participants have been noted. However, her professional knowledge and experience of primary care also influenced the study in a broader sense. Indeed, being a general practitioner with a particular interest in sexual health was a factor in the original idea for the study. She was particularly well placed to explore issues relating to primary care with both sets of participants. In so doing she was able to draw upon her knowledge of the way in which general practice services are organised, and the potential for HIV testing to be more widely available.

6.3.3. Ethical considerations

Throughout the design and conduct of this study the researcher was aware of her ethical responsibilities, being particularly sensitive to the vulnerability and disempowerment faced by some of those who were being researched. She was keenly aware of the need to avoid contributing to racial division by reinforcing stereotypes, and attempted to avoid giving further ammunition to those who appear to perceive African migrants as a burden.[301;302] Rather, her intention was to work in ways which were acceptable to African communities, being willing to listen to the voices of her participants and to seek solutions with them.[28]

The issue of participant confidentiality was particularly important in this study, both because of the sensitive nature of the research subject and because at least some of those who agreed to participate had a diagnosis of HIV infection, which they had not widely disclosed. Particular care was taken by the researcher to ensure that the she did not volunteer any information about an individual's participation in the study.

On a number of occasions the researcher had cause to reflect upon the crucial importance of confidentiality. For example, the interviewer was aware that of two cousins participating in the study, both of whom were infected with HIV, only one cousin knew the status of the other. On another occasion it emerged

during an interview that the participant's husband, who had a history of domestic violence, was unaware that his wife had attended a group for HIV-infected African women, against his express instruction. The interviewer had been introduced to the participant and arrangements for the interview had been made at a meeting of that particular group. It was therefore very important that this information was not inadvertently divulged, the interviewer feeling a duty of care to the participant and recognising the crucial importance of respecting the trust that had been given.

The researcher was aware throughout the study period of the sensibilities around immigration issues. As Kesby has pointed out: *'researchers in the contemporary British context need to be particularly careful because a highly charged atmosphere surrounds immigration issues'*[28] It emerged that some study participants were in the country illegally and the researcher held this information to be privileged, and that she was ethically bound to protect it.[262] The sensitivity around confidentiality was reinforced to the researcher when it became apparent that one of the respondents was using a false name.

The Local NHS Research Ethics Committee reviewed the study and was satisfied that it was not exploitative of a vulnerable group of people.

6.4. Implications for policy, practice and future research

6.4.1. Implications for policy

HIV amongst African communities in the UK is a major public health concern; the number of new diagnoses continues to increase year on year, presentation is often late in the disease and it is thought that around a third of African people living with HIV are currently unaware of their infection. A number of calls have been made for targeted prevention work with African communities, a need that is recognised by the Department of Health[15;22;136] Reducing undiagnosed HIV

infection through the promotion of HIV testing is a key component of primary and secondary prevention.

However, African people may predominantly view HIV testing as a diagnostic rather than a screening tool, with this study demonstrating that it is symptomatic disease that often prompts a move towards HIV testing. There is thus a need for voluntary HIV testing to be prioritised as a routine part of clinical care for African people. There may be lessons to be learnt from the improvement in detection rates achieved following the introduction of universal voluntary antenatal HIV screening; 92% of HIV infected pregnant women were diagnosed prior to delivery in 2004 increasing from 71% in 2000.[9] Many African people are registered with a general practitioner and this study points to the potential for HIV testing to be used for screening in this setting. The competing priorities and complexity of life identified by this study suggests that HIV testing may not be high on the agenda of African people, yet many would be willing to accept an HIV test, prior to the onset of symptoms, if it were to be offered. Further, this study shows that offering an HIV test on the basis of country of origin is broadly acceptable to African people if they are aware of the benefits of testing and if there remains a choice.

Although this study points to the potential benefits of a greater role in HIV testing within general practice, there are a number of issues that need to be addressed. Although HIV testing is a 'level 1' service in the National Strategy for Sexual Health and HIV, that is it should be available in every general practice, there is wide variation in the actual availability of HIV testing in practice.[15] Appropriate training and resources will need to be available if all general practitioners are to meet this requirement, as this study shows that the quality of clinical care and the provision of HIV testing within primary care varies considerably. Further, as recognised by the Health Select Committee of the House of Commons, recent changes to the General Medical Services contract (through which GPs are remunerated for their work) pays insufficient regard to the provision of sexual health services.[303] In particular, under the new GP

contract payments are affected by a system of quality points which reward the achievement of high standards in certain priority clinical conditions. There are no quality points available for sexual health within the essential services that GPs must provide. This 'quality framework' provides the potential to incentivise the use of HIV testing as a screening tool within general practice by attaching a quality point to the offer of HIV testing to African people.

Other writers have expressed concern that the promotion of HIV testing amongst African men is particularly limited and that the greater proportion of African women than men currently identified as living with HIV may be in part a reflection of the success of the antenatal testing strategy which, by definition, offers testing only to women.[10;22] This thesis has highlighted that African men, as well as women, are likely to be registered with a GP and there might therefore be particular advantages to promoting voluntary HIV testing through primary care. It would also help to overcome the stated difficulties that secondary care specialists sometimes encounter in trying to encourage male partners of HIV infected women to come forward for testing.

The government has repeatedly asserted that it is necessary to protect the NHS from 'health tourists'. Government policy restricts access to NHS care to people who have been legally resident in the UK for more than 12 months and maintains that HIV, unlike other sexually transmitted infections, is not exempt from this stipulation.[304;305] Although having no publicly available data as evidence, the government claims that a number of Africans with HIV infection migrate to the UK specifically to access HIV treatment. The findings of this study support the position adopted by the Terence Higgins Trust, namely that far from seeking treatment soon after arrival in the UK many African people do not present to services until they have been in the UK for some time, often at a late stage of the disease, and further, that prior to being tested for HIV, many are unaware of the availability of antiretroviral medication.[306]

This study has underlined the role of stigma as a barrier in accessing HIV testing. Making HIV testing more widely available in general practice and other settings

may help to normalise it, so that it becomes seen more like any other chronic infection. The majority of HIV tests in the UK are undertaken in genitourinary medicine clinics, which may themselves be difficult for some African people to access given the taboo nature of sex and the strong association within African communities between HIV and 'promiscuous' sexual behaviour.

The findings of this study suggest that knowledge of the benefits of being tested and knowing one's HIV status among Africans in Bristol is, at best, patchy. In particular, there was limited knowledge about the benefit of accessing treatment and it being most effective if started before the immune system is too severely depleted. Those who were HIV positive had often gained their knowledge of treatment after being tested late in the course of the disease and some of those who remained untested had no knowledge of the benefits of antiretrovirals. Those who had undertaken an HIV test despite a lack of symptoms, and had subsequently discovered they were not infected with the virus, were generally more aware of treatment availability prior to testing than the groups of participants who had either been tested as a result of ill health or who had not undertaken an HIV test at all. It is therefore likely that raising awareness of the benefits of antiretroviral treatment amongst African communities would aid the increase of uptake of HIV testing.

Further, it was felt by many respondents that there was very little focus on public health messages regarding HIV in the UK, and this prompted calls for more publicity and advertising campaigns. The current provision of HIV health promotion and HIV prevention strategies targeting African communities has been criticised for the limited use of research to inform HIV prevention interventions.[24;128] The findings of this study contribute to understanding the health promotion needs of African communities by identifying that health promotion work must include improvement in personal risk assessment by African people. This study also highlights that campaigns designed to promote HIV testing should particularly focus on the benefits of early diagnosis and treatment, and provide information regarding the asymptomatic stage of disease.

The use of multiple media including bill boards, television, leaflets and local community events have all been suggested. Such an approach if sensitively handled could help to further normalise the infection and to undermine the negative effects of stigma.

The role of faith communities and in particular Christian churches is a largely untapped potential resource according to the findings of this study. Religious belief and church attendance are important aspects of life for many African people. Yet often it was felt that HIV infection could not be openly acknowledged or discussed within churches. Not only could the church become a greater source of support for those living with HIV but also they are potential settings within which HIV testing could be promoted. If this potential is to be realised there may be challenges to overcome; some faith groups may be wary of supporting initiatives relating to sexual practices and as this study suggests, some African people may be reluctant to disclose their HIV status in church. However, statutory providers of sexual health services could usefully consider working together with leaders of faith groups to promote HIV testing and to provide them with information and support.

6.4.2. Implications for clinical practice

The findings of this study demonstrate the high importance clinicians generally attach to acting in the best interest of their patients and show that professionals aim to be both compassionate and supportive. However, they sometimes struggle to understand the worldviews of African people and this can lead to frustration. This study provides insights into the knowledge, beliefs and attitudes of African people that, if disseminated, may help clinicians' understanding. In particular, clinicians who recognise the importance of religion for many African people may be better placed to promote the benefits of Western medicine as complementary to a belief in God. Similarly, clinicians should be aware that some African people might believe that their religious faith protects them from being infected with HIV. It is also important for clinicians to at least

consider the possibility that African patients may be using African herbs sent from home and to be aware of the influence of health beliefs that incorporate a belief in witchcraft or curse. Sensitive exploration of these beliefs within a consultation might be helpful.

One of the most important contributions of this study is the finding that offering an HIV test on the basis of country of origin is broadly acceptable to African people. Although some clinicians expressed concern that this might be interpreted as racist and expressed caution about targeting patients in this way, this study provides important reassurance that when proper explanation is given, the clinician-patient relationship need not be undermined. Coupled with the finding that primary care is seen by professionals and Africans as an appropriate location for discussions about HIV and for HIV testing, this has particularly important implications for general practitioners and their clinical staff. This study suggests that GPs should consider offering an HIV test to all patients whose country of origin is in sub-Saharan Africa, and that incorporating this into consultations with newly registered patients would be particularly beneficial in the task of increasing the uptake of HIV testing amongst African communities.

However, it will be important for clinicians to pay close attention to their communication and relationship with African people. This study suggests that the way in which the HIV test is discussed might be an important determinant of whether it is accepted. African participants have stressed that it must be clear that the choice remains with them and also that they would be more likely to respond positively if they felt relaxed with their doctor and if they were able to trust that the doctor was acting in their best interests in offering the test.

An important aspect of this communication is the need to explain the benefits of knowing one's HIV status even if not suffering symptoms of disease. In particular clinicians should be aware that many African people have a view of HIV that was formed in a context where disease-modifying treatment was unavailable and many have seen friends and relatives die as a result. Clinicians

who address their patients' fear of HIV infection being a death sentence may help their patients to overcome some of their worst fears about HIV infection, pointing to the benefits of antiretroviral treatments especially when commenced before the immune system is severely compromised. The enormous potential to encourage the uptake of HIV testing in this way is borne out by the consistent claims of participants in this study that they would have been likely to test at an earlier stage if they had known about treatment and if the impetus to test had been provided. It is particularly noteworthy that even in the context of a research interview, some African people determined to seek testing for the first time on becoming aware of the availability of antiretroviral drugs.

Confidentiality is a key concern and it is important not only that confidentiality is ensured but also that African patients are reassured that this is the case. All staff, including receptionists, must be versed in the imperative of maintaining patient confidentiality.

The accounts of some participants, both professionals and Africans, included examples of poor medical treatment and delay in diagnosis because of unrecognised risk or unrecognised HIV related symptoms. They point to the need for improved clinical competency and training. The extent of these training needs will require further exploration as discussed below.

6.4.3. Implications for further research

This study found that it is possible to engage African men and women in research into a sensitive subject in a setting outside of the capital. It begins to bridge gaps in the literature both in terms of understanding the epidemiologically based reports of increasing numbers of HIV infected Africans, and in looking beyond the traditional setting of London as the focus of African residents and HIV related work. However, recruitment was challenging and time-consuming and those engaged in future qualitative research amongst similar groups of participants are advised that access to these groups requires the building of networks and time spent in the field prior to detailed data collection.

The study provides further support for claims that that research with ethnic minorities can be undertaken by a researcher of a different ethnic background to those being researched, and may even carry some advantages.[250;300]

This study has raised a number of issues that will require further investigation. If the potential for primary care clinicians to have an increased role in promoting voluntary HIV testing is to be realised, it will be important for research to be undertaken to assess the training needs of GPs, especially in the light of examples in this study of possibly inadequate knowledge relating to HIV. It will also be important to investigate how this training might be best delivered and by whom.

From the perspective of African participants it appears that offering HIV testing within primary care to newly registered African people is broadly acceptable. Before this approach can be properly recommended a number of questions relating to the feasibility and effectiveness of screening for HIV in this context will need to be addressed. A pilot study involving a small number of practices is recommended as a first step. For example, this will enable an assessment of the additional consultation time involved and the rate of uptake of testing in the pilot practices. An important aspect of the pilot study will be to explore the views and experiences of GPs who offer the test, and of African patients who both accept and decline the offer.

The study sought to research the perspectives of professionals with particular expertise and experience in the field of HIV. GPs, being non-specialists, were therefore not amongst those interviewed in this research (with the exception of a single participant who was both a GP and a specialist clinician in HIV medicine). However, the findings of this study should now be supplemented by further research amongst non-specialist clinicians. In particular there is now a need to assess the views of GPs to voluntary HIV testing offered on the basis of country of origin, especially in the light of the broad acceptability of this approach to African people. Since most GPs work closely with their practice nurses, further

investigation should also specifically seek nurses' views about their potential role in the HIV testing process.

The findings of this study highlight the importance of faith groups in the lives of African people. Many regularly attend a place of worship, although it has emerged that the discussion of HIV within these contexts may be limited. The potential role of religious leaders needs further investigation particularly in relation to their views in working with health promotion specialists to promote HIV testing. The findings of this study suggest that HIV is stigmatised within faith groups and this needs further exploration to gain greater understanding of the nature and extent of this phenomenon and for appropriate interventions to be devised to help overcome prejudice where it exists.

6.5. Summary

This chapter has drawn together the findings from both sets of interviews, setting them in the context of previous studies and other published literature. In some areas it is the case that this study has confirmed existing findings, particularly in relation to the multiple challenges faced by African people, yet it also extends these findings by examining perspectives in more detail and by integrating African and professional views. It also makes a major contribution by considering culturally acceptable opportunities for improving the uptake of voluntary HIV testing by African communities in the UK.

The importance of these findings, to a large extent, depends upon the quality and rigour of the methodological approach adopted in attaining them. This chapter has therefore provided an assessment of the research process, including the reflexivity required of good quality qualitative research.

Finally, the chapter has outlined the implications of the study's findings, highlighting their importance for policy, clinical practice and future research.

CHAPTER 7. CONCLUDING COMMENTS

7.1. Introduction

The purpose of this final chapter is to provide a brief overview of the whole thesis and a summary of the contribution this study has made to research into improving the uptake of HIV testing in UK African communities.

7.2. Summary of the thesis

The overall aim of the study was to address the question of how to improve the uptake of voluntary HIV testing by UK African communities. The study did not set out directly to demonstrate that any particular intervention or interventions would improve the uptake of testing, but rather to address the question in broad terms. 'Improving the uptake of voluntary HIV testing in UK African Communities', the title of this thesis, was the focus of concern throughout the research process, being at the heart of every aspect of this enquiry.

The review of the literature in Chapter 2 set this question in its context; it presented and reviewed the evidence for why this enquiry is so important, and provided a review of the academic literature that forms the background to the research. The review served also to clarify the research questions and to crystallize the objectives of the study: to explore the experiences, knowledge and attitudes of professionals and African people to HIV testing; to elucidate perceived barriers to testing for Africans in the UK; and to consider ways to overcome them.

Chapter 3 discussed the methodological approach and empirical methods used to address these questions. Adopting a qualitative methodology allowed an in-depth exploration of a wide range of open-ended topics, and the design of the study enabled these areas to be explored from a range of perspectives.

Data from interviews with professionals and African participants were presented in Chapters 4 and 5. They were drawn together, compared and discussed in the light of the literature in Chapter 6, where implications for policy, practice and further research were considered.

The findings of this study, when considered together, provide a flavour of the complexities of the issues involved in attempting to improve the uptake of HIV testing in UK African communities. In addition to being of academic sociological, philosophical and even theological interest the study's findings also have practical application. They provide new insights for a wide range of research users including policy-makers, health professionals and African interest groups and may contribute to attempts to improve the uptake of HIV testing by UK African communities.

7.3. The contribution of this study

The study comprised a number of original features. First, in contrast to earlier work which has focused on the epidemiology of HIV in UK African communities, the in-depth interviews enabled exploration of the 'why' behind the widely recognised late presentation of disease. Whilst, other qualitative studies have helped to elucidate the lived experiences of African people living with HIV, this study appears to be the first to focus particularly on issues relating to testing. Uniquely it has allowed exploration of the views and perceptions of different groups of African people to HIV testing, those who have and have not tested. This has resulted in a better understanding of the key issues which will need to be resolved if the uptake of HIV testing is to be improved.

Second, the setting for the study is itself an important feature of its design. Much of the research around HIV has been conducted in London, where the majority of new cases of infection are diagnosed. Increasingly, new HIV diagnoses in African people are seen in areas like Bristol, yet previous research has not reached beyond a small number of other centres, and HIV services have traditionally been focused in London. Bristol, in reflecting the national picture, is

unremarkable in terms of its African community and its increasing HIV diagnoses. This is precisely what makes the choice of setting for this research so important.

Third, the two sets of interviews in this study have enabled the barriers to HIV testing in African communities to be explored from the perspectives of both professionals and African people. The data illuminate the burden of disease felt by those providing services as well as by those infected with the virus. The study has shown the close intertwining of themes from the two sets of interviews whilst also highlighting the tensions between them.

Fourth, the study does not limit itself to representing the current situation, important as it is to better understand the perceived barriers to HIV testing. Its explicit aim was to ask how the uptake of HIV testing in African communities could be improved and has identified a number of potentially important ways by which this might be achieved. Further, it has explored these proposals with African people to assess their acceptability. Thus, for example, the perceptions of professionals that it is racist to offer a test targeted to people from Africa emerges as broadly acceptable to African people. This serves as a valuable reminder that whilst we may think we are acting to protect the interests of others, sometimes our perceptions of their perceptions are not always accurate.

Fifth, this study has specifically explored issues around HIV testing in primary care. It was clear as the interviews progressed that many African participants had experience of primary care services and that for many this was extensive. This appears to be the first qualitative study of HIV testing undertaken by a practising GP who has personal experience of the workings of general practice and insight into the possibilities afforded by GP colleagues to promote HIV testing. This perspective influenced both the methodology employed and the interpretation of subsequent findings.

7.4. Closing remarks

The aim of the study was to identify ways of increasing the uptake of HIV testing in UK African communities. As the research progressed, the complexity of this apparently simple aim unfolded; it became increasingly clear that HIV testing, important as it may be, cannot be distilled and separated from the rest of lived experience, difficult and painful as it had often been. The researcher who engages with lives that have known depth of fear and suffering does not leave the field unchanged. It is in beginning to glimpse the perspective of another that we are most truly open to change.

Perhaps one the greatest barriers yet to be overcome is the attitude of society at large. Stigma around HIV remains deeply rooted. For African people living in the UK this is compounded by prejudice and racial discrimination, often borne out of suspicion and ignorance. The researcher's access into the lives of African people in this study was privileged indeed, yet setting out their accounts in this thesis enables others to look over her shoulders, and see remarkable people who have suffered much.

Was mich nicht umbringt, macht mich stärker. [a] *(Nietzsche)*

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[a] That which does not kill me makes me stronger

APPENDIX 1. AIDS DEFINITIONS

AIDS definitions

The definition of AIDS has changed over the years as it has become recognised that the disease has a wide range of clinical manifestations. In 1982 the Centers for Disease control (CDC) in the USA developed its first AIDS case definition, based on the presence of particular diseases indicative of underlying cellular immunodeficiency without other known cause.[32;40] This was adopted by the World Health Organization (WHO) in 1985.[32;40] In 1987 the CDC definition was revised to place greater emphasis on HIV infection status; to include additional indicator diseases; and to accept the presumptive diagnosis of some of the indicator diseases. This definition was subsequently accepted by WHO.[41] Accordingly, AIDS is defined as an illness characterised by the presence of one or more indicator diseases. Where there is no laboratory evidence of HIV infection (the patient has not been tested or the results are inconclusive) and in the absence of another cause of immune deficiency, a definitive diagnosis of the specific diseases listed in Figure 13 is indicative of AIDS. Where there is laboratory evidence of HIV infection, other indicator diseases that require a definitive or in some cases only a presumptive diagnosis, also constitute a diagnosis of AIDS as shown in Figure 14.

In the USA the Centers for Disease Control extended the definition of AIDS in 1993 to include all persons who are severely immunosupressed (a CD4 count of less than 200 x 10^6 cells/l) regardless of the presence of an indicator disease.[42] This definition has not been accepted in the UK and Europe where the diagnosis continues to be made on clinical grounds based on the indicator diseases specified.

Figure 13: AIDS defining conditions without laboratory evidence of HIV[41]

Diseases diagnosed definitively:

- Candidiasis: oesophagus, trachea, bronchi or lungs
- Crytococcosis: extrapulmonary
- Cryptosporidiosis with diarrhoea persisting > 1 month
- Cytomegalovirus disease other than in liver, spleen, nodes
- Herpes simplex virus (HSV) infection
  - Mucocutaneous ulceration lasting > 1 month
  - Pulmonary, oesophageal involvement
- Kaposi's sarcoma in patient < 60 years of age
- Primary cerebral lymphoma in patient < 60 years of age
- Lymphoid interstitial pneumonia in child < 13 years of age
- *Mycobacterium avium:* disseminated
- *Mycobacterium kansasii:* disseminated
- *Pneumocystis carinii* pneumonia
- Progressive multifocal leucoencephalopathy
- Cerebral toxoplasmosis

Figure 14: AIDS defining conditions with laboratory evidence of HIV[41]

Diseases diagnosed definitively:

- Recurrent/multiple bacterial infections in child < 13 years of age
- Coccidiomycosis: disseminated
- HIV encephalopathy
- Histoplasmosis: disseminated
- Isoporiasis with diarrhoea persisting > 1 month
- Kaposi's sarcoma: at any age
- Primary cerebral lymphoma: at any age
- Non-Hodgkin's lymphoma
- Any disseminated mycobacterial disease other than *M tuberculosis*
- *Mycobacterium Tuberculosis*
- Salmonella septicaemia: recurrent
- HIV wasting syndrome
- Recurrent pneumonia within 1 year
- Invasive cervical cancer

Diseases diagnosed presumptively

- Candidiasis: oesophagus
- Cytomegalovirus retinitis with visual loss
- Kaposi's sarcoma
- Mycobacterial disease: disseminated
- *Pneumocystis carinii* pneumonia
- Cerebral toxoplasmosis

A clinical case definition is required in resource poor areas where diagnostic facilities are limited, such as in much of sub-Saharan Africa. A provisional case definition was developed at a WHO workshop on AIDS held in Bangui, Central African Republic in October 1985 and adopted in a slightly modified form by WHO in 1986, becoming known as the "Bangui definition".[40;307] As understanding of the spectrum of severe HIV-related illness in both developed and developing countries subsequently grew, and with the increased availability of laboratory diagnostic testing, the Bangui definition was further modified in 1994 and renamed the WHO AIDS surveillance case definition (see Figure 15). At the same time, an expanded WHO AIDS surveillance case definition was introduced to take account of a positive HIV antibody test where available (see Figure 16).[308]

Figure 15: WHO AIDS case definition for AIDS surveillance[308]

For the purposes of AIDS surveillance an adult or adolescent (> 12 years of age) is considered to have AIDS if at least two of the following major signs are present in combination with at least one of the minor signs and if these signs are not known to be due to a condition unrelated to HIV infection.

Major signs

- Weight loss ≥ 10% of bodyweight
- Chronic diarrhoea for > 1 month
- Prolonged fever for > 1 month (intermittent or constant)

Minor signs

- Persistent cough for > 1 month*
- Generalised pruritic dermatitis
- History of herpes zoster
- Oropharyngeal candidiasis
- Chronic progressive or disseminated herpes simplex infection
- Generalised lymphadenopathy

*For patients with tuberculosis, persistent cough for > 1 month should not be considered as a minor sign.

The presence of either generalised Kaposi's sarcoma or cryptococcal meningitis is sufficient for the diagnosis of AIDS for surveillance purposes.

Figure 16: Expanded WHO case definition for AIDS surveillance[308]

For the purposes of AIDS surveillance an adult or adolescent (>12 years of age) is considered to have AIDS if a test for HIV antibody gives a positive result, and one or more of the following conditions are present:

- ≥ 10% body weight loss or cachexia, with diarrhoea or fever, or both, intermittent or constant, for at least 1 month, not known to be due to a condition unrelated to HIV infection
- Cryptococcal meningitis
- Pulmonary or extrapulmonary tuberculosis
- Kaposi's sarcoma
- Neurological impairment that is sufficient to prevent independent daily activities, not known to be due to a condition unrelated to HIV infection (e.g. trauma or cerebrovascular accident)
- Candidiasis of the oesophagus (which may be presumptively diagnosed based on the presence of oral candidiasis accompanied by dysphagia)
- Clinically diagnosed life threatening or recurrent episodes of pneumonia, with or without aetiological confirmation
- Invasive cervical cancer

APPENDIX 2. PROFESSIONAL PARTCIPANTS

Professional Participants by role and sector

Identifier	Gender	Professional role	Sector
H1female	Female	Sexual Health Advisor	GU Medicine
H2male	Male	Nurse Specialist / Sexual Health Advisor	HIV/GU Medicine
H3male	Male	Sexual Health Advisor	GU Medicine
M1female	Female	Midwife Specialist Trainer	Midwifery
D1female	Female	HIV Specialist Doctor and GP	HIV Medicine
D2male	Male	Consultant Genitourinary Medicine	GU Medicine
D3male	Male	Consultant HIV Medicine	HIV Medicine
V1female	Female	African Community Outreach Worker	Voluntary Agency
V2female	Female	Manager of Voluntary Sector Agency	Voluntary Agency
P1female	Female	Health Promotion Specialist (Sexual Health)	Primary Care Trust
P2female	Female	Sexual Health Commissioner	Primary Care Trust
S1female	Female	Social Worker	Social Services

APPENDIX 3. AFRICAN PARTICIPANTS BY HIV STATUS AND COUNTRY OF ORIGIN

African Participants by HIV status and country of origin

(Listed in chronological order of interviews)

Identifier	Gender	Country of origin	Age	HIV status
K1H+female	Female	Kenya	37	Positive
K2H-male	Male	Kenya	23	Negative
Na1H-female	Female	Namibia	21	Negative
Zi1H-female	Female	Zimbabwe	25	Negative
Zi2H-male	Male	Zimbabwe	28	Negative
Za1Umale	Male	Zambia	21	Unknown
Co1H-male	Male	Congo	37	Negative
Zi3H+female	Female	Zimbabwe	23	Positive
Zi4H+female	Female	Zimbabwe	30	Positive
Zi5H+female	Female	Zimbabwe	28	Positive
M1H+female	Female	Malawi	28	Positive
Za2H+female	Female	Zambia	43	Positive
Zi6H+female	Female	Zimbabwe	38	Positive
Zi7H+male	Male	Zimbabwe	32	Positive
Zi8H+male	Male	Zimbabwe	46	Positive
Zi9H+male	Male	Zimbabwe	36	Positive
Zi10H+female	Female	Zimbabwe	40	Positive
M2H+male	Male	Malawi	41	Positive
B1H+male	Male	Botswana	41	Positive
Zi11Umale	Male	Zimbabwe	28	Unknown
S1Umale	Male	South Africa	27	Unknown
I1Umale	Male	Ivory Coast	40	Unknown
Ni1Umale	Male	Nigeria	35	Unknown
Zi12H+male	Male	Zimbabwe	32	Positive (unconfirmed)
Zi13H-male	Male	Zimbabwe	34	Negative
Ca1H-female	Female	Cameroon	32	Negative

Sampling for maximum variation achieved diversity in age, gender, HIV status and country of origin. The relatively large proportion of Zimbabwean participants reflects the current population of migrants from sub-Saharan Africa currently resident in Bristol.

APPENDIX 4. AFRICAN PARTICIPANTS' SUMMARY OF ROUTE TO HIV TESTING

Identifier	HIV status	Summary of route to HIV testing	Testing site
K1H+female	Positive	Raped in Kenya. Sick on arrival in UK. Taken by friend to GU clinic. CD4 count 30 at diagnosis. Concurrent syphilis.	GU clinic
K2H-male	Negative	Asymptomatic. Proactively sought HIV testing at GU clinic after discovering partner infected.	GU clinic
Na1H-female	Negative	Asymptomatic. Proactively sought HIV test from GP. Told to make appointment at GU clinic.	GU clinic
Zi1H-female	Negative	Asymptomatic. She approached GP to ask for testing after 3 years of thinking about it. Worried about partner's unfaithfulness. Tested by GP.	GP surgery
Zi2H-male	Negative	Asymptomatic. Proactively sought HIV test at GU clinic but could not get an appointment for over a month. Tested by GP	GP surgery
Za1Umale	Unknown	Not registered with a GP. Has never been tested for HIV	Not tested
Co1H-male	Negative	Screening test undertaken by GP after being registered for 18 months.	GP surgery
Zi3H+female	Positive	Antenatal HIV screening test at 25 weeks gestation following delay in finding GP surgery which would permit her to register	Midwife at GP surgery
Zi4H+female	Positive	Symptomatic HIV disease. She attended her GP practice on multiple occasions. Treated as asthma. Deterioration over several months. Admitted to hospital. Diagnosed with HIV and TB.	Hospital inpatient
Zi5H+female	Positive	Husband was diagnosed with HIV as an inpatient. He kept his diagnosis from her for 3 months. Following his disclosure she was tested at the HIV outpatient clinic	HIV medicine outpatient clinic
M1H+female	Positive	Symptomatic HIV disease. She attended her GP regularly for 3 months with deteriorating symptoms. Was told she would be referred to tropical diseases specialist. Appointment came for GU clinic. Very low CD4 count at diagnosis. Deterioration and hospital admission resulted.	GU clinic
Za2H+female	Positive	Symptomatic. She tested in the USA following repeated flu-like illnesses.	USA
Zi6H+female	Positive	Symptomatic. She attended GP almost weekly with increasing haematuria and pain for 6 months. Felt her symptoms were ignored. Eventually tested for HIV 5 weeks after hospital admission. Low CD4 count at diagnosis.	Hospital inpatient

Identifier	HIV status	Summary of route to HIV testing	Testing site
Zi7H+male	Positive	Symptomatic. Attended GP who gave antibiotics. He deteriorated and was admitted to hospital Emergency Department. Diagnosed with TB and subsequently HIV as an inpatient	Hospital inpatient
Zi8H+male	Positive	Symptomatic. Admitted to hospital with CMV retinitis, cerebral lymphoma and spinal abscess. Inpatient for 18 months	Hospital inpatient
Zi9H+male	Positive	Symptomatic. Attended GP for treatment. After several visits, with health deteriorating, the GP advised HIV test and he was told to attend GU clinic. CD4 count 30 when diagnosed. Ill health resulted in 3 month's hospital admission.	GU clinic
Zi10H+female	Positive	Symptomatic. Had been attending GP for 6 months with symptoms including rash. Eventually sought HIV testing at GU clinic at the suggestion of a friend. CD4 count < 30 at diagnosis	GU clinic
M2H+male	Positive	Had previously tested positive for HIV in Sweden. Initially denied status. Several years later approached GP in UK and asked for testing. Tested by GP.	GP surgery
B1H+male	Positive	Symptomatic. 6 months with persistent boil and lymphadenopathy. Repeated visits to GP. Eventually referred to Dental hospital and surgeons. Dental hospital advised he attend GU clinic for HIV test.	GU clinic
Zi11Umale	Unknown	Registered with a GP for 2 years. Has never been tested for HIV	Not tested
S1Umale	Unknown	Been registered with a GP for 5 years. Had been thinking about HIV testing for several months. Eventually asked GP for HIV test and was told to attend GU clinic. Several months later had still not attended.	Not tested
I1Umale	Unknown	Registered with a GP. Has never been tested for HIV	Not tested
Ni1Umale	Unknown	Registered with a GP. Had a set of 'routine' blood tests. Assumed they included HIV although from his account it seems unlikely that was the case.	Not tested
Zi12H+male	Positive (unconfirmed)	Symptomatic. Advised by friend to attend GU clinic. Waited for 6 months before returning to get results. Initial HIV test positive. Further 4 months waiting for hospital follow up and confirmation because of missed appointment.	GU clinic
Zi13H-male	Negative	Asymptomatic. Proactively sought HIV testing from his GP. Tested by GP	GP surgery
Ca1H-female	Negative	Asymptomatic. Asked GP for HIV test after she had nursed a fellow asylum seeker through her terminal AIDS illness. Had to insist on being tested.	GP surgery

APPENDIX 5. PROFILES OF AFRICAN PARTICIPANTS

K1H+female

This 37 year old Kenyan woman was born into a poor family in a rural part of Kenya. She is educated up to Standard Seven (penultimate year of primary school) and worked as a 'house-girl'. She married a man from a different area (Nyeri) whose family ascribed to traditional religious and cultural practices (Mongeki) although he, like the participant, was a Christian. His family did not approve of the marriage but for 11 years there was little contact. K1H+female and her husband had three children, a boy and two girls. When the oldest daughter was thought to be old enough 'the Mongeki' came to circumcise her and attempted to do the same to the participant. Her harrowing account reported that her daughter was raped and subsequently died, and that her husband was shot and killed whilst trying to protect them. The participant was subjected to a vicious sexual assault. After the attack she was seriously unwell, and was helped by a previously unknown married couple. The husband brought her to Bristol where she was taken into the home (a bed-sit) of a Burundian woman. She was still very unwell and was taken by her new friend to the GU clinic where she was diagnosed to be infected with HIV and syphilis. She was initiated on therapy immediately because her CD4 count at this time was 30 x 10^6 cells/l. She is currently seeking asylum and is living in hostel accommodation provided by the National Asylum Service and receiving £5 per day for food via Refugee Action. Her two remaining children are 'somewhere hiding' in Kenya.

K2H-male

This 23 year old Kenyan man came to the UK to study for a degree in Financial Accounting, having previously obtained a degree in Economics in Nairobi. His current studies are being funded by his father who is a senior civil servant in

Kenya. His current girlfriend is infected with HIV. He discovered this when a friend, who works as a Health Care Assistant in the hospital, reported that he had seen her attending an HIV clinic. She initially denied it but after his reassurances that he wouldn't leave her, told him it was so. He subsequently accessed HIV testing at the genitourinary medicine clinic and knows that he is not infected. He remains with his girlfriend. He intends to return to Kenya at the end of his studies.

Na1H-female

This participant is a 21 year old single woman from Namibia. She is educated to 'A' level standard and wishes to pursue further studies when finances allow. She came to the UK on a British Government scheme enabling Namibian young people to work or travel in the UK for a period of two years. No funding is provided and her parents helped her raise money for the flight. Her visa permits her to work. She is currently employed in two jobs; as a Care Assistant in a nursing home and 'after hours' as a cleaner. She does not have a partner in the UK but had been sexually active in Namibia. She would ideally like to save enough money to enable her to undertake a degree course in the UK at the end of two years working in the UK.

Zi1H-female

This 25 year old married woman from Zimbabwe left her husband and five year old son in her own country in order to study in the UK. She decided to come to Bristol because her two sisters are living in the city. Her husband runs his own printing business. She would like to stay in the UK on a long term basis even though she is missing her son, and her husband does not wish to join her here. She is currently on a student visa and is undertaking a computing course and supporting herself financially by working 20 hours per week as a Health Care Assistant. She believed that she might have been exposed to HIV because whilst

she was living with her husband he was unfaithful to her and had other sexual relationships.

Zi2H-male

This 28 year old Zimbabwean man came to Bristol to undertake a course in Media Studies and is funded by his parents to do so. His mother farms their small holding and his father is an international truck driver, travelling across Africa. His was invited to come by his cousin who was already living in Bristol and since his arrival has been joined by his brother with whom he shares a single bed-sit. He has four sisters all of whom remain in Zimbabwe. He works as a Health Care Assistant to help fund his course and living expenses. In Zimbabwe he had a number of different jobs, latterly in marketing working for an international bank and then for the Zimbabwe Broadcasting Company. He has a diploma in marketing but his ambition is to return to Zimbabwe and set up his own recording studio.

Za1Umale

This 21 year old male student from Zambia came to the UK to take a Media Studies course. His father works for the Botswanian Government and the family have been living in Botswana since Za1Umale was ten years old. His married sister settled in the UK several years before his arrival, and works as a hairdresser. She found the course for him, helps to finance it and he lives in her home. To help fund his course he works in a shop in the evenings and weekends. He intends to return to Botswana after further studies. He had one brief sexual relationship in Botswana and has not had a partner since arriving in the UK.

Co1H-male

This 37 year old married man from the Democratic Republic of Congo has been in the UK for four years and now has refugee status. He fled from the Congo and

now suffers from post traumatic stress disorder. He was reluctant to discuss details about his reasons for leaving. His wife and twelve year old son joined him in the UK a year ago and his wife is now pregnant. He is now studying English, which is his third language. The family lives in a rented house with only one decorated room. He disclosed that he had extramarital sexual relationships whilst in the Congo and agreed to be tested when it was suggested by his GP. He is currently unable to return to the Congo.

Zi3H+female

This 23 year old participant from Zimbabwe came to the UK to join her sister who works as a nurse. She was educated to 'A' Level standard and undertook a certificate in book keeping and accountancy in Zimbabwe. She felt that the opportunities for her in Zimbabwe were limited and that it was difficult to get a job. Originally she came to the UK on a visitor's visa but intended to train as a nurse. Her sister lives in Bristol and her mother, who also works as a nurse in Bristol, 'comes and goes'. On arrival she lived first in Cambridge where she undertook an 'Access to Nursing' course. Whilst there she had a year-long relationship with a Zimbabwean man who was a student nurse. When she became pregnant she moved to Bristol to live with her sister and intended to return to Cambridge to live with her partner once the baby was born. However, they are no longer in contact, following her disclosure of her HIV status. She now lives with her 3 month old baby in a bed-sit provided by social services and has little contact with her family. She is seeking leave to remain in the UK.

Zi4H+female

This 30 year old Zimbabwean woman had a successful career as a musician in Zimbabwe before coming, with her partner of several years' standing, to the UK. Her partner came to take up a computing job in London and she intended to study for a degree in music. She comes from a musical family of 11 children, her father being a saxophonist. She was a singer, dancer and drummer in a well

known band and earned enough money to help fund her younger brothers' and sisters' school fees and to pay for an extension to her parent's house. Her partner left the UK when his work took him to Angola. She remained in the UK because they were not yet married and she wished to continue her studies. Her partner subsequently told her to return to Zimbabwe as he wanted to 'pay the bride price' to her parents. In 2003 they had a 'customary marriage'. It was later arranged that they would have a registry office marriage in the UK although he returned to Angola prior to the wedding taking place and she has been unable to contact him since. She had previously been contacted by a woman who claimed that she had been having an affair with him. Having discovered that she was infected with HIV, the woman advised Zi4H+female to undertake testing. Zi4H+female ignored this advice because, at the time, she didn't believe the claim about her partner, who denied the relationship.

She became progressively unwell and was subsequently diagnosed at a relatively late stage of the disease, resulting in a long hospital admission and requiring treatment for TB. Two weeks before the interview she received news that one of her sisters in Zimbabwe had died, probably of HIV related disease.

Zi5H+female

This 28 year old participant from Zimbabwe lives with her HIV infected Zimbabwean husband and is seeking leave to remain in the UK. She and her husband originally came to the UK to visit his brother. During the visit her husband became unwell, was admitted to hospital and eventually diagnosed as infected with HIV. He disclosed his status to her three months later and she subsequently discovered that she was also infected with HIV. At the time of the interview they had been in the UK for two years and were still seeking leave to remain. There trip had originally been intended to be brief and their young son did not accompany them. She has not been able to see her four year old son for two years. Her husband has 3 children from a previous marriage, his first wife

having died of an undiagnosed illness which the participant thinks was probably AIDS related. They have now been married for five years.

She was brought up first by her grandmother in a rural part of Zimbabwe, then by her mother's sister in the town. Her parents divorced when she was young and she doesn't know her father at all. She was educated to primary level and then undertook basic secretarial training.

She and her husband are both working illegally in a factory that produces washing machines. They have no other source of income whilst they seek leave to remain in the UK. Her husband is a heavy drinker and is especially violent towards her when he has been drinking. She feels trapped in her current situation and has suffered from depression over recent months.

M1H+female

This 28 year old participant from Malawi is a qualified 'Enrolled Nurse'. She had worked as a nurse in Zimbabwe for a number of years before being invited by her aunt in Durham to come to the UK. She had hoped to convert her qualifications so as to work as a registered nurse in the UK. However, her qualifications were not recognised and she therefore undertook an 'Access' course in Durham, before moving to Bristol to begin a nursing qualification in learning disabilities. Her studies were suspended when she became increasingly unwell and was eventually diagnosed with HIV infection.

Za2H+female

This 44 year old Zambian woman had 3 siblings before the death of her younger brother in Zambia two years ago. Following her secondary education she went to college in the USA in her mid twenties. She remained there to work for 9 years in total, meeting and marrying her British born husband there before settling in the UK in 1995. She lives now with her 19 year old son, having separated from her husband 2 years ago. She is currently studying to become a Chartered

Accountant whilst working as a trainee accountant. She had an HIV test in the USA and was diagnosed as infected with the virus in 1995. At the time she was not married to her partner who tested negative. Their planned marriage went ahead. She returns to Zambia most years to visit her family but has no plans to leave the UK where she has permanent residency.

Zi6H+female

This participant from Zimbabwe is 38 and has been in the UK for 5 years. She went first to Northampton to stay with her brother, undertaking an 'Access to Nursing' course for one year, later moving to Bristol to begin a college course in mental health nursing. She has a 14 year old daughter who is living in Northampton with her brother. Zi6H+female travelled widely before deciding to come to the UK for further studies. She worked for an airline and took advantage of free flights to visit European cities on a number of occasions. She had decided that to further her career she needed to undertake a degree level qualification in tourism. Having started a course she changed her mind and decided to train as a nurse.

Zi7H+male

This participant from Zimbabwe is 32 years old and has been in the UK for a year. He worked as a wildlife tour guide in the Zimbabwe during which time he met his wife, a UK national, who was running a small tourist business. He came to the UK following his fiancé's return to the UK because the political situation in Zimbabwe made their livelihood difficult to maintain. He became ill and was diagnosed HIV positive in hospital. His fiancé is not infected, although they have been together for six years. They are now married and he works as a fork lift truck driver. They hope to return to Zimbabwe when the political situation is more stable there.

Zi8H+male

This 46 year old Zimbabwean man, who has a wife and three children, is currently a hospital inpatient. He had been admitted 18 months prior to the interview and been seriously ill with cerebral lymphoma, spinal abscess and retinitis.

He is a well educated man who worked as a lawyer in Zimbabwe. For political reasons, he had been forced to leave his job prior to coming to the UK. He came to the UK to visit one of his daughters who was a university student. During the visit he became unwell and was admitted to hospital. His illness caused him to outstay his visitor's visa. His immigration status remains uncertain, he has no recourse to support from Social Services and has received bills from the hospital for his treatment, which he has no means of paying.

Zi9H+male

This 36 year old Zimbabwean man comes from a family of 8 siblings. He has a sister in London and a brother in Bristol. He is well educated and worked for an engineering company in Zimbabwe before travelling to the UK to visit his sister and brother. During the visit he became unwell and was eventually found to be infected with HIV and to have a low CD4 count. He is married and his wife, who subsequently tested positive for HIV, remains in Zimbabwe. Their 8 month old son died of pneumonia in Zimbabwe shortly after Zi9H+male came out of hospital. He assumes that his son's death was HIV related. He remains in the UK to access treatment, but is not permitted to work. Because of immigration restrictions, his wife is unable to join him.

Zi10H+female

This 40 year old Zimbabwean participant has been in the UK for two years. She has 4 children from two broken marriages. Aged between 19 and 5 years old, the children remain in Zimbabwe being looked after by two housemaids and a

gardener. She has a brother and sister in Zimbabwe and two sisters in Bristol with whom she currently lives. She worked as a debt collector in Zimbabwe, but being a member of the opposition party she found it increasingly difficult to provide for her children. Because she did not have a ZANU-PF card, she could not purchase certain items and she felt her prospects were limited. She decided to join her sisters in Bristol. She now works to send money back to her children at home and has indefinite leave to remain in the UK. Her children do not know that she is infected with HIV and she is particularly worried about her five year old son who she fears may be infected with the virus.

M2H+male

This 41 year old Malawian participant originally came to the UK in 1989 to study Marine Engineering. He met his British born second wife at that time, separating from his first wife with whom he had two children in Malawi. His first wife subsequently died of poisoning. M2H+male believes this was suicide on her part, although he claims she would have poisoned him if he had returned to Malawi at that time. His two young children were brought up by his sister.

He has worked on a number of ships and has been based in several parts of the UK and Europe. He returned to Malawi for some time with his second wife and she remained in the village whilst he travelled with his job. He believes that she was unfaithful to him during that time, having multiple sexual relationships. He worked in Sweden for some time where he was found to be HIV positive although he denied the diagnosis for several years. He and his wife came to the UK again five years ago before she finally left him. He now lives with his 15 year old daughter and does casual jobs.

B1H+male

This 41 year old college lecturer from Botswana came to the UK three years ago to undertake a PhD on literacy difficulties in Botswana. He teaches Tswana in Botswana and is married with three children. He has returned to Botswana four times since arriving in the UK, to undertake his research and to see his family. He is funded by the Botswanan Government to undertake his studies and intends to return to his home and former job upon completion of his thesis.

Zi11Umale

This 28 year old Zimbabwean man comes from a family of 10 children. He came to the UK seeking asylum from the political situation in Zimbabwe. He has been granted refugee status. Three of his siblings have settled in South Africa whilst the rest of his family remain in Zimbabwe.

He shares a bed-sit with another Zimbabwean man and is studying for a degree in Information Technology whilst doing two part time jobs (data capture and fork lift truck driving).

S1Umale

This South African participant is 27 years old and has been in the UK for five years. His mother and four brothers live in South Africa. He came to the UK to earn money to support them. He has worked in factory jobs for most of the time and intends to return home within the next twelve months. In South Africa he worked as a professional photographer which led him into multiple sexual relationships. He currently has a girlfriend from Botswana.

I1Umale

This 40 year old participant from the Ivory Coast has been in the UK for 13 years. He has a UK born girlfriend and they have a 6 week old baby. In Ivory Coast he

worked as an entertainer and came to the UK hoping to work in this country as an entertainer. His mother is a traditional healer.

He suffered a racist attack several years ago when he was badly beaten by four white men who broke into his home. This has affected him badly and he carries a lot of fear. He works a little as an entertainer at community events and festivals and occasionally in schools and colleges.

Ni1Umale

This 35 year old Nigerian man has been in the UK for four years, following two years of living in Holland. He left Nigeria because he wanted to travel and plans to return home in the next couple of years to farm his family's land. He is in the UK on a student visa but is working in a warehouse and has not undertaken any studies. He has an English girlfriend and they are expecting a baby.

Zi12H+male

This 32 year old Zimbabwean man is an asylum seeker who has been in the UK for two years. He worked as a musician in Zimbabwe where he played the drums in and sang in a band. He was forced to leave the country when he was accused of singing political songs. He is one of 8 siblings, one sister having died. His father is not alive and as the eldest child he feels financial responsibility towards his family although is unable to work legally in the UK. His family lives in a rural part of Zimbabwe and it is difficult for him to make contact with them by telephone. He became unwell and attended the genitourinary medicine clinic for an HIV test although did not access the results for several months. At the time of the interview had not had a confirmatory HIV test or accessed HIV treatment services.

Zi13H-male

This 34 year old Zimbabwean man has been in the UK for almost three years, being joined by his wife and four year old daughter a year ago. He is the eldest of 6 children and was educated to diploma level in Business Studies and Accountancy. He came to the UK to undertake a degree in Business Studies but had to drop out when he couldn't afford the fees. He is now working as a Tenancy Support Worker with people with mental health problems and has a four year work permit. At present he feels unable to return to Zimbabwe because, having left to come to the UK, he would be treated with suspicion. This has affected his family at home and his father has had to leave the country; his truck driving is now in South Africa. Whilst in Zimbabwe he worked as an Accountant for the National Family Planning Council and was given basic training about sexually transmitted infections including HIV.

Ca1H-female

This 32 year old woman from Cameroon is a failed asylum seeker, currently being supported by the charity of a local Catholic church. Her husband in Cameroon was involved in a political opposition party. Her father had also been involved in the opposition movement and twelve years earlier Ca1H-female had received burns to her arms when acid was thrown over her. As a result she had avoided direct involvement in the opposition but was arrested, and beaten whilst in jail, on account of her husband's involvement. She was helped to escape and came to the UK three years ago to seek asylum. Subsequently she heard that her husband had been shot and killed. She has three children aged nine, six and three who are being looked after by her mother. She is well educated, with a degree in Business Administration and was employed as a systems manager for a shipping company. She is not permitted to work in the UK and spent two months in a detention centre when her application for asylum was denied. Her solicitor secured her release and she is currently appealing against the decision, fearful for her life if she is forced to return to Cameroon.

APPENDIX 6. TOPIC GUIDE USED WITH PROFESSIONALS

Introduction

- Give introduction and provide background to the research, including its purpose and anticipated length of the interview. Assure of anonymity/confidentiality. Obtain written consent including consent to record.

Background details about the informant

- Description of informant's professional role and experience relating to HIV. Specifically explore role in HIV testing. Relationship with other professionals in the field.
- Description of knowledge and experience of working with African people in relation to HIV.

General background to HIV nationally and locally

- What's happened nationally and locally in relation to HIV in recent years – say, in the last five years?
- What, if anything, is different about the numbers/backgrounds of people being tested for HIV?
- How does a person access HIV testing and care in Bristol?

Focusing on HIV in African people

- What are the main reasons for testing and route to testing (eg STI screening, illness, antenatal, contact/partner of HIV+)?
- Can you identify particular characteristics of African people with HIV locally (e.g. countries of origin, how long have they been in country, occupation, immigration status, stage of illness, any other characteristics)?
- When you raise the subject of HIV testing what is the response (probe for e.g. their perception of their risk/ knowledge of the disease/ treatment)? If they decline what are the reasons?
- Are you aware of particular cultural factors or issues when dealing with African people?

Improving the uptake of HIV testing amongst Africans

- What, if any, are the barriers to HIV testing for African people? How can they be overcome?
- Are there opportunities to improve the uptake of HIV testing by African people? (Probe – e.g. primary care, outreach clinics, information/education)
- Are African patients generally registered with a GP or accessing health services elsewhere?
- What is the role of GPs in HIV testing? Could this be expanded?
- What do you feel about targeted voluntary HIV testing based on country of origin?

Conclusion

- Any other issues

APPENDIX 7. TOPIC GUIDE USED WITH AFRICAN PARTICIPANTS

Introduction

- Give introduction and provide background to the research, including its purpose and anticipated length of the interview. Assure of anonymity/confidentiality. Obtain written consent including consent to record.

Background details about the participant

- Age and family background, country of origin, reason for migration, length of time in UK, educational level/ occupation, immigration status.
- Current social and economic circumstances. Explore issues relating to being a migrant. Future plans.

Knowledge and experience of HIV

- HIV in country of origin. Explore experience and knowledge. Explore HIV related beliefs and practice in country of origin.
- Knowledge of disease presentation, risk factors, prognosis, treatment. (If HIV positive explore knowledge prior to testing)

HIV testing (For participants who have undergone an HIV test)

- When and where did you have an HIV test? What was the result?
- What made you decide to get a test? Why at that time? Were you surprised by the result? Can you take me through what happened?
- Explore perception of personal risk at time of testing, knowledge of HIV and benefits of testing.
- Who else knows about your test result? What support is available to you?
- What do family/friends/community think about HIV? Are there any particular issues discussing HIV.
- On balance, are you pleased that you had the test? What are the things that could have been done better? Do you feel you would have benefited it you had taken the test before you actually did?

HIV testing (for participants who have not been tested)

- Have you ever considered being tested for HIV?
- What might make you think about undertaking a test?
- Are there any benefits of being tested for HIV? If so, what are they?
- If you wanted an HIV test, how would you go about it?

Improving the uptake of HIV testing

- What would have encouraged you to test sooner (or if untested, to consider testing)?
- Do you think African people are at any higher risk of carrying the infection than other groups in the UK? If so, why? Do you know African people who you would want to encourage to be tested?
- Do you think the health service could do more to make the test more widely available/easier to access? If so, how?
- Are you registered with a GP? Have you consulted the GP (probe for details) How easy/difficult was it to register with a GP. Does your GP know about your HIV status/test (if tested)? Could GPs be more involved in offering HIV testing. (Probe – how, when)
- How would you feel if a health professional suggested you consider an HIV test because you come from an African country? Would you be offended if you were offered the test because you are African?

Conclusion

- Any other issues

APPENDIX 8. COLLABORATION AND ETHICAL APPROVAL

Collaboration

From the earliest stages of study design, and throughout the research process, a number of individuals and organisations collaborated in the research project. Such collaboration provided helpful forums for discussion and advice, as well as facilitating access to a number of individuals and organisations whose views and experience would prove important.

Formal collaborators in the project were:

- The Milne Centre - Genitourinary Medicine Clinic
- Terence Higgins Trust South West - HIV/AIDS support charity
- North Bristol NHS Trust HIV Service

Informal collaborators included the Bristol Zimbabwe Association and the *Ujima FM* Community Radio Project.

Ethical Approval

The study was granted ethics approval from the United Bristol Healthcare Trust Ethics Committee on 26th February 2003 (Approval Reference Number E5550). All written material (study information leaflets and consent forms for African and professional participants) were approved by the Committee prior to the commencement of fieldwork. Arrangements were made for the translation of written material and for interpreters to be available for interviews if required. Neither of these provisions was required; all participants had a good command of English and none elected for the interview to be conducted in another language.

Locality approval was granted by Southmead Local Research Ethics Committee in March 2003. North Bristol Primary Care Trust and Bristol South and West

Primary Care Trust also granted approval for the research in accordance with the requirements of research governance.

In May 2004 a further submission was made to the Ethics Committee in relation to the financial reimbursement of research participants. The Committee agreed that the sum of £20 could be paid to research participants to reimburse them for their time and travel. In particular, the Committee was satisfied that this did not amount to an inappropriate inducement. Publicity material and amended information sheets were approved by the Committee.

BIBLIOGRAPHY

(1) Barre-Sinous F, Chermann JC, Rey F, Nugeyre MT, Chamaret S, Gruest J et al. Isolation of a T-lymphocytic retrovirus from a patient at risk for acquired immune deficiency syndrome (AIDS). Science 1983; 220(4599):868-871.

(2) Marx JL. Strong new candidate for AIDS agent. Science 1984; 224(4648):475-477.

(3) Frankel AD, Young JAT. HIV-1: fifteen proteins and an RNA. Annual Review of Biochemistry 1998; 67:1-25.

(4) McMichael A. HIV: T cell responses to HIV. Current Opinion in Immunology 2000; 12:367-369.

(5) Nuwayhid NF. Laboratory tests for detection of Human Immunodeficiency Virus Type 1 infection. Clinical and Diagnostic Laboratory Immunology 1995; 2(6):637-645.

(6) Egger M, May M, Chene G, Phillips AN, Ledergerber B, Dabis F et al. Prognosis of HIV-1 infected patients starting highly active antiretroviral therapy: a collaborative analysis of prospective studies. The Lancet 2002; 360(9327):119-129.

(7) Palella FJ, Delaney KM, Moorman AC, Loveless MO, Fuhrer J, Satten GA et al. Declining Morbidity and Mortality among Patients with Advanced Human Immunodeficiency Virus Infection. New England Journal of Medicine 1998; 338(13):853-860.

(8) Weller IVD, Williams IG. Antiretroviral drugs. British Medical Journal 2001; 322(7299):1410-1412.

(9) The UK Collaborative Group for HIV and STI Surveillance. Mapping the issues. HIV and other sexually transmitted infections in the United Kingdom: 2005. London: Health Protection Agency Centre for Infections; 2006.

(10) Sinka K, Mortimer J, Evans B, Morgan D. Impact of the HIV epidemic in sub-Saharan Africa on the pattern of HIV in the UK. AIDS 2003; 17(11):1683-1690.

(11) Health Protection Agency. HIV and AIDS in the United Kingdom quarterly update: data to the end of March 2006. Commun Dis Rep CDR Weekly [serial online] 2006; 16(17).

(12) Barlow D, Daker-White G, Band B. Assortative sexual mixing in a heterosexual clinic population - a limiting factor in HIV spread? AIDS 1997; 11(8):1039-1044.

(13) Burns FM, Fakoya AO, Copas AJ, French PD. Africans in London continue to present with advanced HIV disease in the era of highly active antiretroviral therapy. AIDS 2001; 15(18):2453-2455.

(14) Sabin CA, Smith CJ, Gumley H, Murphy G, Lampe FC, Phillips AN et al. Late presenters in the era of highly active antiretroviral therapy: uptake of and responses to antiretroviral therapy. AIDS 2004; 18(16):2145-2151.

(15) Department of Health. Better prevention, Better services, Better sexual health. The National Strategy for sexual health and HIV. London: Department of Health; 2001.

(16) Bayer R. Public health policy and the AIDS epidemic. An end to HIV exceptionalism? New England Journal of Medicine 1991; 324(21):1500-1504.

(17) Chadborn TR, McGarrigle CA, Waight PA, Fenton KA. Trends in, and determinants of, HIV testing at genitourinary medicine clinics and general practice in England, 1990-2000. Sex Transm Infect 2004; 80(2):145-150.

(18) De Cock KM, Johnson AM. From exceptionalism to normalisation: a reappraisal of attitudes and practice around HIV testing. British Medical Journal 1998; 316(7127):290-293.

(19) Manavi K, Welsby P. HIV testing should no longer be accorded any special status. British Medical Journal 2005; 330(7490):492-493.

(20) Singh S, Dunford A, Carter YH. Routine care of people with HIV infection and AIDS: Should interested general practitioners take the lead? British Journal of General Practice 2001; 51:399-403.

(21) King M, Petchey R, Singh S, Wright L, Raab J, Farnsworth W et al. The role of the general practitioner in the community care of people with HIV infection and AIDS: a comparative study of high- and low-prevalence areas in England. British Journal of General Practice 1998; 48:1233-1236.

(22) Department of Health. HIV and AIDS in African communities: a framework for better prevention and care. London: Department of Health; 2005.

(23) Communicable Disease Surveillance Centre. HIV infection and AIDS in the United Kingdom: monthly report - July 2001. CDR Weekly 2002; 12(30).

(24) Chinouya M. HIV prevention and African communities living in England: A study of challenges in service provision. National AIDS Trust: 2001.

(25) Office for National Statistics. Census 2001. London: HMSO Crown copyright; 2004.

(26) Office for National Statistics. Neighbourhood Statistics. Crown Copyright; 2003 [cited 2006 July 8]; Available from: http://snipurl.com/stnk

(27) Gompels M, Dooley D. North Bristol NHS Trust HIV Services Report 2004 - 2005. North Bristol NHS Trust; 2005.

(28) Kesby M, Fenton K, Boyle P, Power R. An agenda for future research on HIV and sexual behaviour among African migrant communities in the UK. Social Science and Medicine 2003; 57:1573-1592.

(29) Hymes KB, Greene JB, Marcus A, William DC, Cheung T, Prose NS et al. Kaposi's Sarcoma in homosexual men - a report of eight cases. Lancet 1981; 318:598-600.

(30) Gottlieb MS, Schroff R, Schanker HM, Weisman JD, Fan PT, Wolf RA et al. Pneumocystis Carinii pneumonia and mucosal candidiasis in previously healthy homosexual men. New England Journal of Medicine 1981; 305(24):1425-1431.

(31) Marx JL. New disease baffles medical community. Science 1982; 217(4560):618-621.

(32) Centers for Disease Control and Prevention. Current trends update on acquired immune deficiency syndrome (AIDS) - United States. Morbidity and Mortality Weekly Report 1982; 31(37):507-514.

(33) Masur H, Michelis MA, Greene JB, Onorato I, Vande Stouwe RA, Holzman RS et al. An outbreak of community acquired Pneumocystis Carinii pneumonia. New England Journal of Medicine 1981; 305(24):1431-1438.

(34) Centers for Disease Control and Prevention. Opportunistic infections and Kaposi's Sarcoma among Haitians in the United States. Morbidity and Mortality Weekly Report 1982; 32(26):353-354,360-361.

(35) Centers for Disease Control and Prevention. Epidemiologic notes and reports. Pneumocystis carinii pneumonia among persons with haemophilia A. Morbidity and Mortality Weekly Report 1982; 31(27):365-367.

(36) Centers for Disease Control task force on Kaposi's Sarcoma. Epidemiologic aspects of the current outbreak of Kaposi's Sarcoma and opportunistic infections. New England Journal of Medicine 1982; 306(4):248-252.

(37) Kamradt T, Niese D, Vogel F. Slim disease (AIDS). Lancet 1985; 326(8469):1425.

(38) Marx JL. A virus by any other name.... Science 1985; 227(4693):1449-1451.

(39) Subcommittee of the International Committee on the Taxonomy of Viruses. What to call the AIDS virus? Nature 1986; 321(6065):10.

(40) World Health Organization. Acquired immunodeficiency syndrome (AIDS): WHO/CDC case definition for AIDS. Weekly Epidemiological Record 1986; 61(10):69-76.

(41) World Health Organization. Acquired immunodeficiency syndrome (AIDS): 1987 revision of CDC/WHO case definition for AIDS. Weekly Epidemiological Record 1988; 63(1):1-8.

(42) Centers for Disease Control and Prevention. 1993 Revised classification system for HIV infection and expanded surveillance case definition for AIDS among adolescents and adults. Morbidity and Mortality Weekly Report 1992; 41(RR17).

(43) Collaborative Group on AIDS Incubation and HIV Survival. Time from HIV-1 seroconversion to AIDS and death before widespread use of highly-active antiretroviral therapy: a collaborative re-analysis. Lancet 2000; 355(9210):1131-1137.

(44) Mindel A, Tenant-Flowers M. Natural history and management of early HIV infection. British Medical Journal 2001; 322(7297):1290-1293.

(45) World Health Organization. Acquired Immunodeficiency Syndrome (AIDS). Interim proposal for a WHO staging system for HIV infection and disease. Weekly Epidemiological Record 1990; 65(29):221-224.

(46) Hirsh VM, Olmsted RA, Murphey-Corb M, Purcell RH, Johnson PR. An African primate lentivirus (SIV_{sm}) closely related to HIV-2. Nature 1989; 339(6223):389-392.

(47) Gao F, Bailes E, Robertson DL, Chen Y, Rodenburg CM, Scott MF et al. Origin of HIV-1 in the chimpanzee *Pan troglodytes troglodytes*. Nature 1999; 397(6718):436-441.

(48) Adler MW. Development of the epidemic. British Medical Journal 2001; 322(7296):1226-1229.

(49) Grant AD, De Cock KM. HIV infection and AIDS in the developing world. British Medical Journal 2001; 322(7300):1475-1478.

(50) Fischl MA, Richman DD, Grieco MH, Gottlieb MS, Volberding PA, Laskin OL et al. The efficacy of Azidothymidine (AZT) in the treatment of patients with AIDS and AIDS-related complex. New England Journal of Medicine 1987; 317(4):185-191.

(51) Porter K, Babiker AG, Darbyshire JH, Pezzotti PBK, Walker AS, CASCADE Collaboration. Determinants of survival following HIV-1 seroconversion after the introduction of HAART. The Lancet 2003; 362(9392):1267-1274.

(52) Del Amo J, Del Romero J, Barrasa A, Perez-Hoyos S, Rodriguez C, Diez M et al. Factors influencing HIV progression in a seroconverter cohort in Madrid from 1985 to 1999. Sex Transm Infect 2002; 78(4):255-260.

(53) Staehelin C, Rickenbach M, Low N, Egger M, Ledergerber B, Hirschel B et al. Migrants from Sub-Saharan Africa in the Swiss HIV cohort study: access to antiretroviral therapy, disease progression and survival. AIDS 2003; 17(15):2237-2244.

(54) Perez-Hoyos S, Del Amo J, Muga R, Del Romero J, De Olalla GP, Guerrero R et al. Effectiveness of highly active antiretroviral therapy in Spanish cohorts of HIV seroconverters: differences by transmission category. AIDS 2003; 17(3):353-359.

(55) Phillips AN, Lepri AC, Lampe F, Johnson M, Sabin CA. When should antiretroviral therapy be started for HIV infection? Interpreting the evidence from observational studies. [Editorial]. AIDS 2003; 17(13):1863-1869.

(56) CASCADE Collaboration. Short-term risk of AIDS according to current CD4 cell count and viral load in antiretroviral drug-naive individuals and those treated in the monotherapy era. AIDS 2004; 18(1):51-58.

(57) Cozzi-Lepri A, Monforte A, Castelli F, Antinori A, de Luca A, Pezzotti P et al. When to start highly active antiretroviral therapy in chronically HIV-infected patients: evidence from the ICONA study. AIDS 2001; 15(8):983-990.

(58) Gazzard B. British HIV Association (BHIVA) guidelines for the treatment of HIV-infected adults with antiretroviral therapy (2005). HIV Medicine 2005; 6(S2):1-61.

(59) World Health Organization. Treating 3 million by 2005: making it happen: the WHO strategy. The WHO and UNAIDS global initiative to provide antiretroviral therapy to 3 million people with HIV/AIDS in developing countries by the end of 2005. Geneva: World Health Organization; 2003.

(60) Bray D. The current status of antiretroviral therapy in Africa. Journal of HIV Therapy 2006; 11(1):7-10.

(61) UNAIDS. AIDS epidemic update 2005: December 2005. Geneva: UNAIDS; 2005.

(62) UNAIDS. Report on the global HIV/AIDS epidemic. Geneva: UNAIDS; 2004.

(63) Gisselquist D, Rothenberg RB, Potterat JJ, Drucker E. HIV infections in sub-Saharan Africa not explained by sexual or vertical transmission. International Journal of STD and AIDS 2002; 13:657-666.

(64) Schmid GP, Buve A, Mugyenyi P, Garnett GP, Hayes RJ, Williams BG et al. Transmission of HIV-1 infection in sub-Saharan Africa and effect of elimination of unsafe injections. The Lancet 2004; 363(9407):482-488.

(65) Communicable Disease Surveillance Centre. HIV and AIDS in the UK. An epidemiological review: 2000. London: CDSC; 2000.

(66) Health Protection Agency. Renewing the focus. HIV and other Sexually Transmitted Infections in the United Kingdom in 2002: an update November 2003. London: HPA; 2003.

(67) Health Protection Agency. The survey of prevalent HIV infections diagnosed (SOPHID): National data for 2004. London: HPA; 2005.

(68) Erens B, McManus S, Prescott A, Field J, Johnson AM, Wellings K et al. National survey of sexual attitudes and lifestyles II. Reference tables and summary report. London: National Centre for Social Research; 2003.

(69) Beardsell S, Coyle A. A review of research on the nature and quality of HIV testing services: A proposal for process-based studies. Social Science and Medicine 1996; 42(5):733-743.

(70) BMA Foundation for AIDS. Take the HIV test. London: BMAIDS Trading Ltd; 1998.

(71) Parry J, Mortimer P, Perry K, Pillay D, Zuckerman M. Towards error-free HIV diagnosis: guidelines on laboratory practice. Communicable Disease and Public Health 2003; 6(4):334-350.

(72) Nicoll A, McGarrigle C, Brady AR, Ades AE, Tookey P, Duong T et al. Epidemiology and detection of HIV-1 among pregnant women in the United Kingdom: results from national surveillance 1988-96. British Medical Journal 1998; 316:253-258.

(73) Connor EM, Sperling RS, Gelber R, Kiselev P, Scott G, O'Sullivan MJ et al. Reduction of Maternal-Infant Transmission of Human Immunodeficiency Virus Type 1 with Zidovudine Treatment. N Engl J Med 1994; 331(18):1173-1180.

(74) Gibb DM, MacDonagh SE, Tookey P, Duong T, Nicoll A, Goldberg D et al. Uptake of interventions to reduce mother-to-child transmission of HIV in the United Kingdom and Ireland. AIDS 1997; 11(7):F53-F58.

(75) Madge S, Singh S. The new imperative to test for HIV in pregnancy. British Journal of General Practice 1998;1127-1128.

(76) Simpson WM, Johnstone FD, Goldberg DJ, Gormley SM, Hart GJ. Antenatal HIV testing: assessment of a routine voluntary approach. British Medical Journal 1999; 318:1660-1661.

(77) NHS Executive. Reducing mother to baby transmission of HIV. HSC 1999/183 ed. London: Department of Health; 1999.

(78) Cliffe S, Tookey PA, Nicoll A. Antenatal detection of HIV: national surveillance and unlinked anonymous survey. British Medical Journal 2001; 323(7309):376-377.

(79) Department of Health. Screening for infectious diseases in pregnancy: standards to support the UK antenatal screening programme. London: Department of Health; 2003.

(80) Goldberg D. Estimated HIV prevalence: vindication of the Department of Health's decision to make HIV an infectious disease priority. Communicable Disease and Public Health 2002; 5(2):90-91.

(81) De Cock KM, Mbori-Ngacha D, Marum E. AIDS in Africa V: Shadow on the continent: public health and HIV/AIDS in Africa in the 21st century. The Lancet 2002; 360(9326):67-72.

(82) Scott GM. HIV antibody test should be a routine investigation for undiagnosed pneumonia. British Medical Journal 1996; 312(7042):1363.

(83) Department of Health. Guidelines for pre-test discussion on HIV testing. PL/CMO/(96)1. London: Department of Health; 1996.

(84) Millar R, Lipman M. HIV pre-test discussion [Editorial]. British Medical Journal 1996; 313:130.

(85) General Medical Council. Serious Communicable Diseases. London: General Medical Council; 1997.

(86) Devroey D, Van Casteren V, Sasse A. How are patients informed about their HIV test results? Fam Pract 2002; 19:125-127.

(87) Devroey D, Van Casteren V, Sasse A, Wallyn S. Non-consented HIV testing by Belgian general practitioners. AIDS 2003; 17(4):637-642.

(88) Lister P. HIV antibody testing should be routine investigation. British Medical Journal 1996; 313:751.

(89) McAdam C, Richardson A, Lewis S, Gore S, Brettle R. Attitudes towards HIV testing of patients attending hospital. International Journal of STD and AIDS 1997; 8(11):729-730.

(90) General Medical Council. Confidentiality: protecting and providing information. London: General Medical Council; 2004.

(91) Aston I. GMC's guidance on HIV infection and AIDS is useful. British Medical Journal 1996; 313:751-752.

(92) De Wildt G, Sweeney H. Moving away from rational medicine? British Medical Journal 1996; 312:1367.

(93) Hayter M. Confidentiality and the acquired immune deficiency syndrome (AIDS): an analysis of the legal and professional issues. Journal of Advanced Nursing 1997; 25:1162-1166.

(94) Wadsworth E, McCann K. Attitudes towards and use of general practitioner services among homosexual men with HIV infection or AIDS. British Journal of General Practice 1992; 42:107-110.

(95) Madge S, Jones M, Mocroft A, Wells H, Johnson AM. Do people attending a same day testing clinic discuss their need for an HIV test with their GP? British Journal of General Practice 1999; 49:813-815.

(96) King MB. AIDS and the general practitioner: views of patients with HIV infection and AIDS. British Medical Journal 1988; 297:182-184.

(97) Ford C, Theobald N. Redefining the role of primary care in HIV. British Journal of General Practice 2000;686-687.

(98) BMA, Association of British Insurers. Medical information and insurance. Joint guidelines from the British Medical Association and the Association of British Insurers. London: BMA; 2002.

(99) Whittet S, Trail P, de Ruiter A, O'Sullivan D, Jones R. General practitioners' attitudes and beliefs on antenatal testing for HIV: postal questionnaire survey. British Medical Journal 2000; 321:934.

(100) Danziger R. HIV testing and HIV prevention in Sweden. British Medical Journal 1998; 316(7127):293-295.

(101) Terrence Higgins Trust. Criminal Prosecution of HIV transmission - THT Policy Statement. Terrence Higgins Trust; 2006 [cited 2006 June 6] Available from: http:/www.tht.org.uk/information resources/ publications/policystatment/prosecutionofhivtransmission.pdf

(102) Gill N. Commentary: Promoting testing is no substitute for recognising risk. British Medical Journal 1998; 316(7127):295-296.

(103) Mortimer PP, Loveday C. The virus and the tests. In: Adler MW, editor. ABC of AIDS. Fifth ed. London: BMJ Publishing Group; 2002. 6-11.

(104) Worthington C, Myers T. Factors underlying anxiety in HIV testing: risk perceptions, stigma and the patient-provider power dynamic. Qual Health Res 2003; 13(5):633-655.

(105) Shriver MD, Everett C, Morin SF. Structural interventions to encourage primary HIV prevention among people living with HIV. AIDS 2000; 14 (S1):S57-S62.

(106) Meadows J, Catalan J, Gazzard B. "I plan to have the HIV test" - predictors of testing intention in women attending a London antenatal clinic. AIDS Care 1993; 5(2):141-148.

(107) Medical Foundation for AIDS and Sexual Health. Recommended standards for NHS HIV services. London: Medical Foundation for AIDS and Sexual Health; 2002.

(108) Ross JDC, Goldberg DJ. Patterns of HIV testing in Scotland: A general practitioners perspective. Scottish Medical Journal 1997; 42:108-110.

(109) Matthews P, Fletcher J. Sexually transmitted infections in primary care: a need for education. British Journal of General Practice 2001; 52:52-56.

(110) Grun L, Tassano-Smith J, Carder C, Johnson AM, Robinson A, Murray E et al. Comparison of two methods of screening for genital chlamydial infection in women attending in general practice: cross sectional survey. British Medical Journal 1997; 315(7102):226-230.

(111) Madge S, Olaitan A, Mocroft A, Phillips A, Johnson M. Access to medical care one year prior to diagnosis in 100 HIV-positive women. Fam Pract 1997; 14:255-257.

(112) Petchey R, Farnsworth B, Williams J. 'The last resort would be to go to the GP'. Understanding the perceptions and use of general practitioner services among people with HIV/AIDS. Social Science & Medicine 2000; 50(2):233-245.

(113) Madge S, Matthews P, Singh S, Theoald N. HIV in Primary Care. London: Medical Foundation for AIDS and Sexual Health; 2004.

(114) Boyton R, Scambler G. Survey of general practitioners' attitudes to AIDS in the North West Thames and East Anglian regions. British Medical Journal 1988; 296(6621):538-540.

(115) Madge S, Mocroft A, Olaitan A, Johnson M. Do women with HIV infection consult with their GPs? British Journal of General Practice 1998; 48:1329-1330.

(116) Fitzpatrick R, Dawson J, Boulton M, Mclean J, Hart G, Brookes M. Perceptions of general practice among homosexual men. British Journal of General Practice 1994; 44:80-82.

(117) Shapiro JA. General practitioners' attitudes towards AIDS and their perceived information needs. British Medical Journal 1989; 298:1563-1566.

(118) Kellock DJ, Rogstad KE. Attitudes to HIV testing in general practice. International Journal of STD and AIDS 1998; 9:263-267.

(119) Hope SC, Theobald JA, McOwan A. Sexual health provision and the sexual health and HIV strategy for England: a questionnaire survey of general practitioners' views. International Journal of STD and AIDS 2002; 13:230-233.

(120) Anderson P, Mayon-White R. General practitioners and management of infection with HIV. British Medical Journal 1988; 296:535-537.

(121) Milne RIG, Keen SM. Are general practitioners ready to prevent the spread of HIV? British Medical Journal 1988; 296:533-535.

(122) Gibb DM, MacDonagh SE, Gupta R, Tookey P, Peckham C, Ades AE. Factors affecting uptake of antenatal HIV testing in London: results of a multicentre study. British Medical Journal 1998; 316:259-261.

(123) Office for National Statistics. Census 2001. National Statistics Online; 2003, Crown Copyright. Available from: http://www.statistics.gov.uk/cci/nugget.asp?id=263

(124) Elam G, Chinouya M. Feasibility study for health surveys among Black African populations living in the UK: Stage 2 - Diversity among Black African communities. London: Joint Health Surveys Unit; 2000.

(125) Chinouya M, Reynolds R. HIV prevention and African communities living in England: A review of the literature. National AIDS Trust: 2001.

(126) McMunn A, Brookes M, Nazroo J. Feasibility study for health surveys in black African populations living in Britain. Stage 1: the demography and geography of black Africans in Britain. London: London Joint Health Surveys Unit. National Centre for Social Research and Department of Health; 1999.

(127) Elam G, McMunn A, Nazroo J. Feasibility study for health surveys among black African people living in England. Final report - implications for the Health Survey for England 2003. London: Joint Health Surveys Unit; 2001.

(128) Department of Health and London HIV Commissioners. HIV prevention and African communities living in England. A framework for action. London: National AIDS Trust; 2003.

(129) Health Protection Agency Centre for Infections and Health Protection Scotland. Unpublished Quarterly Surveillance Tables No. 70, 06/1 Table 12b. 2006.

(130) Del Amo J, Petruckevitch A, Phillips AN, Johnson AM, Stephenson JM, Desmond N et al. Spectrum of disease in Africans with AIDS in London. AIDS 1996; 10:1563-1569.

(131) Del Amo J, Goh BT, Forster GE. AIDS defining conditions in Africans resident in the United Kingdom. International Journal of STD and AIDS 1996; 7:44-47.

(132) O'Farrell N, Lau R, Yoganathan K, Bradbeer CS, Griffin GE, Pozniak A. AIDS in Africans living in London. Genitourinary Medicine 1995; 71:358-362.

(133) Health Protection Agency Centre for Infections and Health Protection Scotland. Unpublished Quarterly Surveillance Tables No. 64: 04/3. 2004.

(134) Communicable Disease Surveillance Centre. Antenatal screening for HIV infection is improving in London. CDR Weekly 2000; 10(8):69.

(135) Dougan S, Gilbart VL, Sinka K, Evans BG. HIV infections acquired through heterosexual intercourse in the United Kingdom: findings from national surveillance. British Medical Journal 2005;1303-1304.

(136) Department of Health. Better prevention, Better services, Better sexual health. The National Strategy for sexual health and HIV. Implementation action plan. London: Department of Health; 2002.

(137) Weatherburn P, Ssanyu-Sseruma W, ickson F, McLean S, Reid D. Project Nasah. An investigation into the HIV treatment information and other needs of African people with HIV resident in England. London: Sigma Research; 2003.

(138) Sullivan AK, Curtis H, Sabin CA, Johnson MA. Newly diagnosed HIV infections: review in UK and Ireland. British Medical Journal 2005;1301-1302.

(139) PHLS Communicable Disease Surveillance Centre, ICH (London), SCIEH. HIV and AIDS in the United Kingdom 2001. An update November 2002. London: Communicable Disease Surveillance Centre; 2002.

(140) Erwin J, Peters B. Treatment issues for HIV+ Africans in London. Social Science and Medicine 1999; 49:1519-1528.

(141) Low N, Paine K, Clark R, Mahalingham M, Pozniak A. AIDS survival and progression in black Africans living in south London, 1986-1994. Genitourinary Medicine 1996; 72:12-16.

(142) Saul J, Erwin J, Bruce JC, Peters B. Ethnic and demographic variations in HIV/AIDS presentation at two London referral centres 1995-9. Sex Transm Infect 2000; 76:215.

(143) Barry S, Lloyd-Owen S, Madge S, Cozzi-Lepri A, Evans A, Phillips A et al. The changing demographics of new HIV diagnoses at a London centre from 1994 to 2000. HIV Medicine 2002; 3:129-134.

(144) Anderson J, Doyal L. Women from Africa living with HIV in London: a descriptive study. AIDS Care 2004; 16(1):95-105.

(145) Morgan D, Mahe C, Mayanja B, Okongo JM, Lubega R, Whitworth JA. HIV-1 infection in rural Africa: is there a difference in median time to AIDS and survival compared with that in industrialized countries? AIDS 2002; 16(4):597-603.

(146) Del Amo J, Petruckevitch A, Phillips A, Johnson AM, Stephenson J, Desmond N et al. Disease progression and survival in HIV-1-infected Africans in London. AIDS 1998; 12:1203-1209.

(147) Del Amo J, Petruckevitch A, Phillips AN, De Cock KM, Stephenson J, Desmond N et al. Risk factors for tuberculosis in patients with AIDS in

London: a case-control study. International Journal of Tuberculosis and Lung Disease 1999; 3(1):12-17.

(148) Department of Health and Refugee Council. Caring for dispersed asylum seekers: a resource pack. Leeds: Department of Health; 2004.

(149) Traore C. African men and access to HIV treatments. Report of an expert seminar. London: Terrence Higgins Trust; 2000.

(150) Pollard AJ, Savulescu J. Eligibility of overseas visitors and people of uncertain residential status for NHS treatment. British Medical Journal 2004; 329(7461):346-349.

(151) HM Government. Immigration and Asylum Act 1999. London: Stationery Office. Crown Copyright; 1999.

(152) Del Amo J, Broring G, Fenton K. HIV health experiences among migrant Africans in Europe: how are we doing? AIDS 2003; 17:2261-2263.

(153) All-Party Parliamentary Group on AIDS. Migration and HIV: Improving lives in Britain. An inquiry into the impact of the UK nationality and immigration system on people living with HIV. All-Party Parliamentary Group on AIDS. Crown Copyright; 2003.

(154) Creighton S, Sethi G, Edwards SG, Miller R. Dispersal of HIV positive asylum seekers: national survey of UK healthcare providers. British Medical Journal 2004; 329(7461):322-323.

(155) Browne A. The secret threat to British lives. The Spectator 2003; Jan 27.

(156) Coker R. Migration, public health and compulsory screening for TB and HIV. Asylum and migration working paper 1. London: Institute of Public Policy Research; 2003.

(157) Doyal L, Anderson J. 'My fear is to fall in love again...' How HIV-positive African women survive in London. Social Science & Medicine 2005; 60(8):1729-1738.

(158) Chinouya M, Davidson O. The Padare Project. Assessing health-related knowledge, attitudes and behaviours of HIV-positive Africans accessing services in north central London. London: African HIV Policy Network; 2003.

(159) MAYISHA II Collaborative Group. Assessing the feasibility and acceptability of community based prevalence surveys of HIV among black Africans in England. London: Health Protection Agency Centre for Infections; 2005.

(160) Doyal L, Anderson J. My heart is loaded. African women with HIV surviving in London. Report of a qualitative study. London: The Health Foundation, Positively women, Queen Mary's School of Medicine and Dentistry at the University of London, Terrence Higgins Trust; 2004.

(161) Chinouya M, O'Keefe E. God will look after us: Africans, HIV and religion in Milton Keynes. Diversity in Health and Social Care 2005; 2:177-186.

(162) Smith GD. Learning to live with complexity: ethnicity, socioeconomic position, and health in Britain and the United States. Am J Public Health 2000; 90(11):1694-1698.

(163) Sundquist J. Migration, equality and access to health care services. J Epidemiol Community Health 2001; 55(10):691-692.

(164) Health Survey for England 2004. The health of minority ethnic groups. Leeds: The Information Centre; 2006.

(165) McMunn A, Mwanje R, Paine K, Pozniak A. Health service utilization in London's African migrant communities: implications for HIV prevention. AIDS Care 1998; 10(4):453-462.

(166) Fenton KA. Strategies for improving sexual health in ethnic minorities. Current Opinion in Infectious Diseases 2001; 14:63-69.

(167) Chinouya M, Davidson O, Fenton K. The Mayisha Study. Sexual attitudes and lifestyles of migrant Africans in inner London. West Sussex: AVERT; 2000.

(168) Beksinska ME, Rees HV, Kleinschmidt I, McIntyre J. The practice and prevalence of dry sex among men and women in South Africa: a risk factor for sexually transmitted infections? Sex Transm Infect 1999; 75(3):178-180.

(169) Elam G, Fenton K, Johnson A, Nazroo J, Ritchie J. Exploring ethnicity and sexual health. London: Social and Community Planning Research, UCL; 2004.

(170) Caldwell JC, Caldwell P, Quiggin P. The social context of AIDS in sub-Saharan Africa. Population and Development Review 1989; 15(2):185-234.

(171) Heald S. The power of sex: Some reflections on the Caldwells' 'African Sexuality' thesis. Africa 1995; 65(4):489-505.

(172) Lurie MN, Williams BG, Zuma K, Mkaya-Mwamburi D, Garnett GP, Sweat MD et al. Who infects whom? HIV-1 concordance and

discordance among migrant and non-migrant couples in South Africa. AIDS 2003; 17:2245-2252.

(173) Fenton KA, Chinouya M, Davidson O, Copas A, MAYISHA Research Team. HIV transmission risk among sub-Saharan Africans in London travelling to their countries of origin. AIDS 2001; 15(11):1442-1445.

(174) Morris M, Kretzschmar M. Concurrent partnerships and the spread of HIV. AIDS 1997; 11:641-683.

(175) Goldin CS. Stigmatization and AIDS: Critical issues in public health. Social Science & Medicine 1994; 39(9):1359-1366.

(176) Kalichman SC, Simbayi L. Traditional beliefs about the cause of AIDS and AIDS-related stigma in South Africa. AIDS Care 2004; 16(5):572-580.

(177) Nicoll A, Killewo J. Science, sense and nonsense about HIV in Africa. Communicable Disease and Public Health 2000; 3(2):78-79.

(178) Brewer DD, Brody S, Drucker E, Gisselquist D, Minkin SF, Potterat JJ et al. Mounting anomalies in the epidemiology of HIV in Africa: cry the beloved paradigm. International Journal of STD and AIDS 2003; 14:144-147.

(179) Gisselquist D, Potterat JJ. Heterosexual transmission of HIV in Africa: an empiric estimate. International Journal of STD and AIDS 2003; 14:162-173.

(180) Gisselquist D, Potterat JJ, Brody S, Vachon F. Let it be sexual: how health care transmission of AIDS in Africa was ignored. International Journal of STD and AIDS 2003; 14:148-161.

(181) Erwin J, Morgan M, Britten N, Gray K, Peters B. Pathways to HIV testing and care by black African and white patients in London. Sex Transm Infect 2001; 78:37-39.

(182) Henley A, Schott J. HIV/AIDS and minority groups. Culture, Religion & Patient Care in a Multi-Ethnic Society. London: Age Concern, England; 1999. 348-368.

(183) Onwumere J, Holtum S, Hirst F. Determinants of quality of life in black African women with HIV living in London. Psychology Health and Medicine 2002; 7(1):61-74.

(184) Malanda S, Meadows J, Catchpole M. Are we meeting the psychological needs of Black African HIV-positive individuals in London? Controlled study of referrals to a psychological medicine unit. AIDS Care 2001; 13(4):413-419.

(185) Goffman E. Stigma: notes on the management of spoiled identity. New York: Prentice-Hall; 1963.

(186) Parker R, Aggleton P. HIV and AIDS-related stigma and discrimination: a conceptual framework and implications for action. Social Science & Medicine 2003; 57(1):13-24.

(187) Dodds C, Keogh P, Chime O, Haruperi T, Nabulya B, Ssanyu Sseruma W et al. Outsider status: stigma and discrimination experienced by Gay men and African people with HIV. London: Sigma Research; 2004.

(188) Flowers P, Davis M, Hart G, Rosengarten M, Frankis J, Imrie J. Diagnosis and stigma and identity amongst HIV positive Black Africans living in the UK. Psychology and Health 2006; 21(1):109-122.

(189) Burns F, Fenton K. Access to HIV care among migrant Africans in Britain. What are the issues? Psychology Health and Medicine 2006; 11(1):117-125.

(190) Palacio H, Kahn JG, Richards TA, Morin SF. Effect of race and/or ethnicity in use of antiretrovirals and prophylaxis for opportunistic infection: a review of the literature. Public Health Reports 2002; 117(3):233-251.

(191) Burns F, Mercer C, Mercey D, Sadiq S. Factors that may increase HIV testing uptake in those who decline to test. Sex Transm Infect 2004; 80:247-249.

(192) Frater AJ, Dunn DT, Beardall AJ, Ariyoshi K, Clarke JR, McClure MO et al. Comparative response of African HIV-1-infected individuals to highly active antiretroviral therapy. AIDS 2002; 16:1139-1146.

(193) Garcia de Olalla P, Knobel H, Carmona A, Guelar A, Lopez-Colomes J, Cayla J. Impact of adherence and highly active antiretroviral therapy on survival in HIV-infected patients. Journal of Acquired Immune Deficiency Syndrome 2002; 30(1):105-110.

(194) AIDS and Mobility. Access to HIV Care and Support for Migrants and Ethnic Minorities in Europe. Brussels: NIGZ, European Project AIDS & Mobility; 2003.

(195) Fenton KA, Chinouya M, Davidson O, Copas AJ. HIV testing and high risk sexual behaviour among London's migrant African communities: a participatory research study. Sex Transm Infect 2002; 78:241-245.

(196) Burns F, Fenton KA, Morison L, Mercer C, Erens B, Field J et al. Factors associated with HIV testing among black Africans in Britain. Sex Transm Infect 2005; 81(6):494-500.

(197) Stone VE. Optimizing the care of minority patients with HIV/AIDS. Clinical Infectious Diseases 2004; 38:400-404.

(198) McMunn A, Mwanje R, Pozniak A. Issues facing Africans in London with HIV infection. Genitourinary Medicine 1997; 73:157-158.

(199) Foss AM, Watts CH, Vickerman P, Heise L. Condoms and prevention of HIV. British Medical Journal 2004; 329:185-186.

(200) Pinkerton SD, Abramson PR. Effectiveness of condoms in preventing HIV transmission. Social Science & Medicine 1997; 44(9):1303-1312.

(201) Power R. The application of qualitative research methods to the study of sexually transmitted infections. Sex Transm Infect 2002; 78:87-89.

(202) Dingwall R, Murphy E, Watson P, Greatbatch D, Parker S. Catching goldfish: quality in qualitative research. Journal of Health Services Research and Policy 1998; 3:167-172.

(203) Snape D, Spencer L. The foundations of qualitative research. In: Ritchie J, Lewis J, editors. Qualitative research practice: a guide for social science students and researchers. London: Sage Publications; 2003.

(204) Denzin N, Lincoln Y. The discipline and practice of qualitative research. In: Denzin N, Licoln Y, editors. The Sage handbook of qualitative research. 3rd ed. London: Sage Publications; 2005.

(205) Bryman A. Quantity and quality in social research. London: Unwin Hyman; 1988.

(206) Jaye C. Doing qualitative research in general practice: methodological utility and engagement. Fam Pract 2002; 19(5):557-562.

(207) Miles MB, Huberman AM. Qualitative data analysis. 2nd ed. London: Sage Publications; 1994.

(208) Harding G, Gantley M. Qualitative methods: beyond the cookbook. Fam Pract 1998; 15(1):76-79.

(209) Barbour RS, WoReN Mo. Acquiring qualitative skills for primary care research. Review and reflections on a three-stage workshop. Part 2: analysing interview data. Fam Pract 2000; 17(1):83-89.

(210) Malterud K. Shared understanding of the qualitative research process. Guidelines for the medical researcher. Fam Pract 1993; 10(2):201-206.

(211) Swingewood A. A short history of sociological thought. Hampshire: The Macmillan Press Ltd.; 1991.

(212) Denzin N, Lincoln Y. Entering the field of qualitative research. In: Denzin N, Lincoln Y, editors. Handbook of qualitative research. 1st ed. Thousand Oaks, CA: Sage Publications; 1994.

(213) Guba E, Lincoln Y. Competing paradigms in qualitative research. In: Denzin N, Lincoln Y, editors. Handbook of qualitative research. 1st ed. Thousand Oaks, CA: Sage Publications; 1994.

(214) Silverman D. Interpreting qualitative data: Methods for analysing, text and interaction. London: Sage Publications; 1993.

(215) Giddens A. New rules of sociological method. 2nd ed. Cambridge: Polity Press; 1993.

(216) Silverman D. Introducing qualitative research. In: Silverman D, editor. Qualitative research: Theory, method and practice. 2nd ed. London: Sage Publications; 2004.

(217) Schwandt T. Constructivist, interpretevist approaches to human inquiry. In: Denzin N, Lincoln Y, editors. Handbook of qualitative research. 1st ed. Thousand Oaks, CA: Sage Publications; 1994.

(218) Hammersley M. What's wrong with ethnography? London: Routledge; 1992.

(219) Wainwright S, Forbes A. Philosophical problems with social research on health inequalities. Health Care Analysis 2000; 8:259-277.

(220) Hammersley M, Atkinson P. Ethnography: principles in practice. 2nd ed. London: Routledge; 1995.

(221) Blumer H. Symbolic interactionalism: perspective and method. Englewood Cliffs: Prentice Hall; 1969.

(222) Holstein JA, Gubrium JF. Phenomenology, ethnomethodology, and interpretive practice. In: Denzin N, Licoln Y, editors. Handbook of Qualitative Research. 1st ed. Thousand Oaks, CA: Sage Publications; 1994.

(223) Cresswell J. Qualitative inquiry and research design: choosing among five traditions. London: Sage Publications; 1998.

(224) Schutz A. The phenomenology of the social world. London: Northwestern University Press; 1967.

(225) Holstein JA, Gubrium JF. Interpretive practice and social action. In: Denzin N, Lincoln Y, editors. The Sage handbook of qualitative research. 3rd ed. London: Sage Publications; 2005.

(226) Donovan J. We don't buy sickness, it just comes. London: Gower; 1986.

(227) Cuff E, Sharrock F. Perspectives in sociology. 3rd ed. London: Routledge; 1992.

(228) Miller J, Glassner B. The 'inside' and the 'outside': finding realities in interviews. In: Silverman D, editor. Qualitative research: theory, method and practice. 2nd ed. London: Sage Publications; 2004.

(229) Flick U. An introduction to qualitative research. 2nd ed. London: Sage Publications; 2002.

(230) Woods P. Symbolic interactionism: theory and method. In: LeCompte M, editor. The handbook of qualitative research in education. San Diego: Academic Press; 1992.

(231) Craib J. Modern social theory. New York: St. Martins Press; 1992.

(232) Cornwell J. Hard earned lives: Accounts of health and illness from East London. London: Tavistock; 1984.

(233) Charmaz K. Grounded theory: Objectivist and constructivist methods. In: Denzin N, Lincoln Y, editors. Handbook of qualitative research. 2nd ed. London: Sage Publishing; 2002.

(234) Green J. Commentary: Grounded theory and the constant comparative method. British Medical Journal 1998; 316(7137):1064-1065.

(235) Strauss AL. Qualitative analysis for social scientists. Cambridge: Cambridge University Press; 1987.

(236) Glaser BG, Strauss AL. The discovery of grounded theory: strategies for qualitative research. Chicago: Aldine de Gruyter; 1967.

(237) Strauss A, Corbin J. Basics of qualitative research: techniques and procedures for developing grounded theory. 2nd ed. London: Sage Publications; 1998.

(238) Charmaz K. Qualitative interviewing and grounded theory analysis. In: Gubrium JF, Holstein JA, editors. Handbook of interview research: context and method. Thousand Oaks, CA.: Sage Publications; 2001.

(239) Spencer L, Ritchie J, O'Connor W. Analysis: practices, principles and processes. In: Ritchie J, Lewis J, editors. Qualitative research practice: a guide for social science students and researchers. London: Sage Publications; 2003.

(240) Strauss A, Corbin J. Grounded theory methodology: an overview. In: Denzin N, Lincoln Y, editors. Handbook of qualitative research. 1st ed. Thousands Oaks, CA: Sage Publications; 1994.

(241) Strauss AL, Corbin J. Basics of qualitative research: Grounded theory procedures and techniques. 2nd ed. California: Sage Publications; 1998.

(242) Gilchrist VJ. Key informant interviews. In: Crabtree BF, Miller WL, editors. Doing qualitative research. London: Sage Publications; 1992.

(243) Fetterman DM. Ethnography: Step by step. London: Sage Publications; 1989.

(244) Britten N, Jones R, Murphy E, Stacy R. Qualitative research methods in general practice and primary care. Fam Pract 1995; 12:104-114.

(245) Mays N, Pope C. Observational methods in health care settings. British Medical Journal 1995; 311:182-184.

(246) Marshall C, Rossman GB. Designing qualitative research. 3rd ed. London: Sage Publications; 1999.

(247) Tremblay MA. The Key Informant technique: a non-ethnographic application. In: Burgess RG, editor. Field research: a sourcebook and field manual. London: Routledge; 1991.

(248) Marshall MN. The key informant technique. Fam Pract 1996; 13(1):92-97.

(249) Goetz JP, LeCompte MD. Ethnography and qualitative design in educational research. London: Academic Press; 1984.

(250) Adamson J, Donovan JL. Research in Black and White. Qual Health Res 2002; 12(6):816-825.

(251) Patton MQ. Qualitative evaluation and research methods. 2nd ed. Newbury Park: Sage Publications; 1990.

(252) Burgess RG. Elements of sampling in field research. In: Burgess RG, editor. Field research: a sourcebook and field manual. London: Routledge; 1991.

(253) Ritchie J, Lewis J, Elam G. Designing and selecting samples. In: Ritchie J, Lewis J, editors. Qualitative research practice: a guide for social science students and researchers. London: Sage Publications; 2003.

(254) Kvale S. InterViews: an introduction to qualitative research interviewing. Thousand Oaks, CA: Sage Publications; 1996.

(255) Chew-Graham CA, May CR, Perry MS. Qualitative research and the problem of judgement: lessons from interviewing fellow professionals. Fam Pract 2002; 19(3):285-289.

(256) Arthur S, Nazroo J. Designing fieldwork strategies and materials. In: Ritchie J, Lewis J, editors. Qualitative research practice: a guide for social science students and researchers. London: Sage Publications; 2003.

(257) Britten N. Qualitative Research: Qualitative interviews in medical research. British Medical Journal 1995; 311:251-253.

(258) Barbour RS, Featherstone VA, WoReN Mo. Acquiring qualitative skills for primary care research. Review and reflections on a three-stage workshop. Part 1: using interviews to generate data. Fam Pract 2000; 17(1):76-82.

(259) Helman C. Research in primary care: the qualitative approach. In: Norton P, Stewart M, Tudiver F, Bass M, Dunn E, editors. Primary care research: traditional and innovative approaches. Newbury Park, CA: Sage Publications; 1991. 105-124.

(260) Miller WL, Crabtree BF. Primary care research: a multimethod typology and qualitative road map. In: Crabtree BF, Miller WL, editors. Doing qualitative research. London: Sage Publications; 1992.

(261) Legard R, Keegan J, Ward K. In-depth interviews. In: Ritchie J, Lewis J, editors. Qualitative research practice: a guide for social science students and researchers. London: Sage Publications; 2003.

(262) Johnson JM. In-depth interviewing. In: Gubrium JF, Holstein JA, editors. Handbook of interview research: context and method. Thousand Oaks, CA: Sage Publications; 2001.

(263) Holstein JA, Gubrium JF. The active interview. In: Silverman D, editor. Qualitative research: theory, method and practice. 2nd ed. London: Sage Publications; 2004.

(264) Oppenheim AN. Questionnaire design, interviewing and attitude measurement. London: Pinter; 1992.

(265) Reason P, Rowan J. Human inquiry: a sourcebook of new paradigm research. Chichester: John Wiley and Sons Ltd.; 1981.

(266) Lewis J. Design issues. In: Ritchie J, Lewis J, editors. Qualitative research practice: a guide for social science students and researchers. London: Sage Publications; 2003.

(267) Ritchie J. The applications of qualitative methods to social research. In: Ritchie J, Lewis J, editors. Qualitative research practice: a guide for social science students and researchers. London: Sage Publications; 2003.

(268) Marshall MN. Sampling for qualitative research. Fam Pract 1996; 13(6):522-525.

(269) Lincoln Y, Guba E. Naturalistic inquiry. London: Sage Publications; 1985.

(270) Kuzel A. Sampling in qualitative inquiry. In: Crabtree BF, Miller WL, editors. Doing qualitative research. London: Sage Publications; 1992.

(271) Adler PA. The reluctant respondent. In: Gubrium JF, Holstein JA, editors. Handbook of interview research: context and method. Thousand Oaks, CA.: Sage Publications; 2001.

(272) Ryen A. Cross-cultural interviewing. In: Gubrium JF, Holstein JA, editors. Handbook of interview research: context and method. Thousand Oaks, CA.: Sage Publications; 2001.

(273) Power R. The role of qualitative research in HIV/AIDS. AIDS 1998; 12:687-695.

(274) Kirk J, Miller ML. Reliability and validity in qualitative research. London: Sage Publications; 1986.

(275) Ritchie J, Spencer L, O'Connor W. Carrying out qualitative analysis. In: Ritchie J, Lewis J, editors. Qualitative research practice: a guide for social science students and researchers. London: Sage Publications; 2003.

(276) Atlas.ti (4.2) Berlin: Scientific Software Development; 1997.

(277) Pope C, Ziebland S, Mays N. Qualitative research in health care: Analysing qualitative data. British Medical Journal 2000; 320(7227):114-116.

(278) Perakyla A. Reliability and validity in research based on naturally occurring social interaction. In: Silverman D, editor. Qualitative research: theory, method and practice. 2nd ed. London: Sage Publications; 2004.

(279) Transcriber (1.5.0) DGA: 2002. Available from: http://www.trans.sourceforge.net

(280) Bryman A, Burgess RG. Developments in qualitative data analysis: an introduction. In: Gantley M, Harding G, Kumar S, Tissier J, editors. An introduction to qualitative methods for health professionals. London: Royal College of General Practitioners; 1999.

(281) Huberman AM, Miles MB. Data management and analysis methods. In: Denzin N, Lincoln Y, editors. Handbook of qualitative research. 1st ed. Thousand Oaks, CA: Sage Publications; 1994.

(282) Dougan S, Patel B, Tosswill JH, Sinka K. Diagnoses of HIV-1 and HIV-2 in England, Wales, and Northern Ireland associated with west Africa. Sex Transm Infect 2005; 81(4):338-341.

(283) Gilbart VL. Late diagnosis of HIV infection among individuals with low, unrecognised or unacknowledged risks in England, Wales and Northern Ireland. AIDS Care 2006; 18(2):133-139.

(284) Chime O. Voices for the future. Unpublished report available from http://ahrf.org.uk/articles/voices1.pdf; 2004.

(285) Mays N, Pope C. Qualitative Research: Rigour and qualitative research. British Medical Journal 1995; 311:109-112.

(286) Altheide DL, Johnson JM. Criteria for assessing interpretive validity in qualitative research. In: Denzin N, Lincoln Y, editors. Handbook of qualitative research. 1st ed. Thousand Oaks, CA: Sage Publications; 1994.

(287) Murphy E, Dingwall R, Greatbatch D, Parker S, Watson P. Qualitative research methods in health technology assessment: a review of the literature. Health Technology Assessment 1998; 2.

(288) Mays N, Pope C. Qualitative research in health care: Assessing quality in qualitative research. British Medical Journal 2000; 320(7226):50-52.

(289) Lincoln Y. Sympathetic connections between qualitative methods and health research. Qual Health Res 1992; 2(4):375-391.

(290) Fielding N, Fielding J. Linking data, qualitative research methods. London: Sage Publications; 1986.

(291) Lewis J, Ritchie J. Generalising from qualitative research. In: Ritchie J, Lewis J, editors. Qualitative research practice: a guide for social science students. 2nd ed. London: Sage Publications; 2003. 263-286.

(292) Cutcliffe J. Methodological issues in grounded theory. Journal of Advanced Nursing 2000; 31(6):1476-1484.

(293) Lee R. Doing research on sensitive topics. London: Sage Publications; 1993.

(294) Dexter LA. Elite and specialized interviewing. Evanston: North Western University Press; 1970.

(295) Ribbens J. Interviewing - An "unnatural situation"? Women's Studies International Forum 1989; 12(6):579-592.

(296) Fontana A, Frey J. Interviewing: the art of science. In: Denzin N, Lincoln Y, editors. Handbook of Qualitative Research. 1st ed. Thousand Oaks, CA: Sage Publications; 1994.

(297) Merton RK. Insiders and outsiders: a chapter in the sociology of knowledge. The American Journal of Sociology 1972; 78(1):9-47.

(298) Scott P. Lay beliefs and the management of disease amongst West Indians with diabetes. Health and Social Care in the Community 1998; 6(6):407-419.

(299) Song M, Parker D. Commonality, difference and the dynamics of disclosure in in-depth interviewing. Sociology 1995; 29(2):241-256.

(300) Rhodes PJ. Race-of-interviewer effects: a brief comment. Sociology 1994; 28(2):547-558.

(301) Kaplan JB, Bennett T. Use of Race and Ethnicity in Biomedical Publication. JAMA 2003; 289(20):2709-2716.

(302) Bhopal R. Is research into ethnicity and health racist, unsound, or important science? British Medical Journal 1997; 314(7096):1751.

(303) House of Commons Health Committee. New developments in sexual health and HIV/AIDS policy. London: The Stationery Office Limited. Crown Copyright; 2005.

(304) Caroline Flint M.P. Minister for Public Health. Address to Conference. Sustaining the Momentum: The African National HIV Conference. 2006.

(305) HM Government. New developments in sexual health and HIV/AIDS policy: Government response to the Health Select Committee's Third Report of Session 2004-2005. London: The Stationery Office Limited. Crown Copyright; 2006.

(306) Terrence Higgins Trust. Westminster Hall briefing on access: note on access to HIV treatment for undocumented migrants and those refused leave to remain; [cited 2006 June 8] Available from: http://www.tht.org.uk/binarylibrary/westminsterhallbriefingonaccess.pdf

(307) World Health Organization. Workshop on AIDS in Central Africa. Bangui, Central African Republic. 22 to 25 October 1985. WHO/CSD/AIDS/85.1. Geneva: WHO; 1985.

(308) World Health Organization. WHO case definitions for AIDS surveillance in adults and adolescents. Weekly Epidemiological Record 1994; 69(37):273-280.